Life without the Royal Senses

Life without the Royal Senses

Kirsten Malmbak

… to focus on the accessible rather than the unattainable

Translated by Karen Steenhard

LIFE WITHOUT THE ROYAL SENSES

Translated from the Danish original
LIVET UDEN KONGESANSER

Edited by Vivian Rea Wittenborn

Layout by Forlagsservice / Mikael Strøm Eriksen
Printed in Denmark by Toptryk

Table of contents

Preface

This book is an account of the life experienced by Kirsten Malmbak, who was born a twin in 1947. She and her sister, Anne, were born deaf and at age seven began learning sign language at a school for the deaf. However, their sight weakened slowly and almost imperceptibly due to Usher syndrome, which left them deafblind as adults.

Kirsten tells her story in a series of remembrances, which give sighted and hearing readers the opportunity to imagine what it might be like to be born deaf and become deafblind as an adult.

What is it like to lack sight and hearing? Many people imagine that it would cut them off from almost everything. Kirsten's book makes it clear that is not the case. Beneath the sensory loss is a person like anyone else, a person who develops in order to experience and enjoy life and share their skills and knowledge. This happens in ways that differ from what is familiar to those of us who have all our senses, so we are surprised when we read how life without sight and hearing can have the qualities, perspectives, joys and sorrows that all of us share.

Kirsten's account of her experiences is not a handbook for deafblindness. Neither is Kirsten's book a poetic re-enactment of her childhood, development and adult life. The book is Kirst-

en's contribution to giving readers interest in and access to her experience and discoveries, which can inspire readers to reflect about her world and compare it to their own.

For most people, experiences are a mixture of the actual events we remember and the language that has maintained them. This is also true for Kirsten. However, Kirsten's language world is also different. Her native language is not spoken Danish, but deaf sign language, which she learned at the school for the deaf and through her communication with other deaf people in adulthood. Kirsten shared her experience through sign language and written notes with Vivian Rea Wittenborn, a personal assistant. It is Vivian's text that forms the basis for the Danish book. The Danish text was translated into English by Karen Steenhard, an American translator who lives in Denmark. Both Vivian and Karen have done their utmost to ensure that Kirsten Malmbak's sign language account of her life is reflected fairly in the Danish and English texts.

We wish to thank the sponsors who provided financial support for the English translation and production of the book:

William Demant Fonden, The Oticon Foundation

SPSK, Langelinje School in Copenhagen

The Association of Danish Deafblind People (FDDB)

CFD (former: Center for Døve)

A private sponsor (NN)

Palle Vestberg, Facilitator, 2021

Foreword

I had never heard the expression *royal senses* until someone explained to me that it refers to sight and hearing. A king uses these two senses to rule his kingdom, because they enable him to see and hear what's going on over a large distance. In contrast, he cannot touch, taste or smell very far into his vast domain. So it is lucky for me that I do not have a kingdom to rule, because today I live through the last three senses. I was born deaf and my sight began to fail when I was a girl.

Only a few years ago, the thought of writing a book had never entered my mind. Gradually, however, I began to toy with the idea of telling others about my life and experiences as a deafblind person. There were matters close to my heart that I was anxious to share with the seeing and hearing world. For courage and inspiration I turned to the few deaf authors whose work I was familiar with, particularly my Swedish friend Ulla-Bell Thorin, who has published a number of books dealing with deafness.

I felt even more encouraged after reading Asger Bergmann's book *Sign language – why not?* soon after its publication on May 13, 2015 to mark the first anniversary of the Danish Parliament's recognition of Danish sign language as an official language. In his

book Asger Bergmann relates many of the challenges he had to overcome in his life due to his deafness. Since I was also born deaf, and identify strongly with the deaf community, I found myself nodding in agreement with many of his stories. Still, my world is different, partly because I grew up in a hearing family, and partly because my life took a different turn when a congenital disease caused me to lose my sight. This double loss and the way it affects the way I interact with the world accounts for the bulk of the challenges I encounter daily. And yet, despite the difficulties of having lived most of my life without the royal senses, I have been fortunate, in that I've had many positive, life-affirming experiences, have been able to develop my interests to the full and have found love – all things that many people would think impossible for someone like me. That explains my desire to give others insight into not only how difficult life can be for a deafblind person, but also how rich life can be if you learn to focus on the things that are accessible, rather than on those that are unattainable.

Inspired and emboldened by the examples of others, I began to think seriously about writing my own book. But that's when I ran up against my first hurdle: I needed an editor. Although I have had a relatively standard education followed by technical training, sign language is my primary language, and written language presents a number of difficulties. Sign language syntax differs from spoken and written language. Determiners (articles, numerals, possessives, demonstratives and quantifiers) are a particular problem, because they are not used separately in sign language.

That meant I needed someone with a good knowledge of written language to help me present my message correctly.

As luck would have it, I met my editor at a course held in May 2016 at the Danish Association of the Blind's center in Fredericia, where the Danish Deafblind Association holds many of its activities. During the last evening at dinner, I mentioned to Gerd Nielsen, one of the blind and hearing-impaired participants, that I wanted to write a book. I was telling her about my problem with finding an editor when a young woman seated at our table suddenly introduced herself to me and, to my surprise and delight, offered her help. The young woman was Vivian Rea Wittenborn, and she was attending the course as a personal assistant for another participant. She turned out to love writing and to have collaborated on books before, which made me feel that we had been destined to work together.

So I had found my editor, and our work together began already that same July. During the writing process, we corresponded frequently by e-mail and met several times where we were able to communicate more directly with the help of a sign language interpreter. The book was finished exactly one year later. I'd like to take this opportunity to heartily thank Vivian Rea Wittenborn for her wonderful editing and extra research on the internet. I would also like to thank my partner, Carsten Thorup, for his great patience while I was preoccupied with my time-consuming writing project. I also wish to thank my sister, Anne Malmbak, whose excellent memory was a great help with many details in the book,

and others who kindly contributed vital information. Despite our painstaking endeavors, however, we were unable to confirm some of the dates in the book, so that I have had to rely solely on my own memory.

I hope my story will provide readers with new information and insight into a world that most people know nothing about. With any luck at all, these new considerations and thoughts will help lessen the distance between the hearing, seeing world and my own.

Kirsten Malmbak, 2017

Home to the twins in their early years, apartment building

A modern five-story building with a balcony for each unit. The family's third-floor apartment is not in view. The picture was taken across a broad street, with a small park featuring a reflecting pool and small fountain in the foreground. Branches from an old willow tree hang like a green waterfall over the water. In the distance is the bell tower belonging to Solbjerg Church, where Anne and Kirsten were christened. The picture was taken on a sunny day in the late afternoon.

Color photo 2020, Ved Andebakken, Frederiksberg. Photographer: Palle Vestberg.

1. Childhood
– born into a silent world

The way my mother tells it, she was heavily pregnant with my sister and me during a heat wave in the summer of 1947. Her legs and feet were so swollen from the heat that she had to borrow my father's size 13 shoes. In fact, my mother was not even sure how many children she was expecting. During a prenatal exam, the doctor speculated as to whether she was expecting twins or just one large baby. There was no such thing as ultrasound scanning in those days, so the doctor had to listen for a heartbeat through a stethoscope, and he assured her that he could hear only one.

When she started to go into labor, she was admitted to the old maternity wing of Rigshospitalet in Copenhagen. Shortly after midnight on August 8, my mother gave birth to her first child, a little girl, my sister Anne. To everyone's surprise, the obstetrician saw that a second baby was on the way. I had been hidden behind my sister throughout the pregnancy, which is why the doctor had heard only her heartbeat. So in the end, my mother gave birth to twins.

Anne and I are fraternal twins and as different as day and night. Even so, we looked very much alike until about the age of three.

Before the 1950s, twin births were rare, and since my parents had expected only one child, they were completely unprepared for two. They immediately rushed out to buy an extra crib and a second set of everything a baby needs, which was no doubt stressful, not to mention a strain on their budget. However, the many photos taken of us testify to the fact that my parents were very proud of their twin girls.

The four of us lived in a small apartment near the city hall in Frederiksberg, an independent municipality in the Capital Region of Denmark. My father was a policeman and my mother a homemaker, although she'd had some business training. Every day she walked Anne and me in a double baby buggy in nearby Frederiksberg Park, where she enjoyed the attention of passersby.

One day when Anne and I were two years old, we were playing together while my mother was cooking. Suddenly she dropped a pot lid, which clattered loudly on the kitchen floor. When she bent down to retrieve it, my mother noticed that my sister and I had not reacted to the sound. Finding it odd, she deliberately dropped the lid again. Once more, Anne and I did not have the slightest reaction.

My worried mother took us to the doctor and told him about dropping the pot lid. After examining us, he regretfully informed my mother that both her daughters were deaf. My mother was shocked and tearful, but there was nothing the doctor could do to help either her or us. There were no special aids or support systems he could refer her to.

She repeated the news to my father, who refused to believe it. His girls looked so vibrant and healthy! At no point had either of them thought there was anything wrong with us. My parents had no knowledge of deaf people or the deaf community, so it must have been difficult for them to know what steps to take. Nor did they know anyone they could approach for guidance or advice.

As luck would have it, my father was often sent to the U.S. in connection with his work in the technical department of the Danish Security and Intelligence Service (PET). As the U.S. was technologically far ahead of Denmark, he received further training in technical development from the CIA. It was a long trip on a prop plane, but it was necessary for my father to stay up to date with the latest technology if he was to continue to work for PET. During one of his trips to the U.S., my father heard about a school that taught deaf children. He contacted the school, which from time to time sent us teaching materials consisting mostly of pictures with words that my mother could use to teach us what language is. I think there were also illustrations with signs from American Sign Language, but that was of no use to us in Denmark, as every country has developed its own sign language. Because this form of deaf instruction was the only training my sister and I received in our early years, neither we nor our parents learned sign language. We had our own way of communicating with each other, however, based on simple gestures.

In the beginning of the 1950s, very few Danes spoke English, so we were lucky that my father did, as he was able to show my

mother how to use the American school materials to teach us basic language skills. My father even had a sideline translating American westerns into Danish.

One day when I was about two-and-a-half years old, my father was sitting at his typewriter, working on a translation. The keys made a resounding clack every time he touched them, so that he couldn't hear what I was doing, not to mention that he was engrossed in his writing. Somehow I managed to push a chair over to the coat rack in the hallway, crawl onto the chair to reach my coat, and saunter out the front door. I suppose I was looking for my mother, who had gone shopping. In any case, I wandered all by myself into the busy street. There weren't many cars in those days, but there were plenty of bicycles, and I could easily have been injured. I couldn't have heard a warning shout or bicyclist's bell, much less an approaching tram or car.

Fortunately, my mother had only gone to a local shop to buy butter, so she wasn't far away. While she was waiting for the clerk to scoop out a mound of butter from a barrel, she glanced out the window and was surprised to see a little girl who closely resembled her own. When she realized that it was in fact her daughter, she ran frantically into the street and grabbed me. I don't remember what happened after that, though I suspect my father got an earful.

After those early years, the apartment was too crowded, so we moved to a large duplex in Lyngby, a suburb north of Copenhagen. The living room and kitchen were on the first floor, along

with a centrally located coal-burning stove. The master bedroom, two small bedrooms and the bathroom were on the second floor. There was also a basement, where we washed clothes and stored coal for the stove.

During the winter, the coalman used to drive up to the house in a truck. Wearing a heavy leather vest to protect his back, he would fill a sack, heave it onto his back, carry it to the house, pour the coal through the basement window and go back to the truck for more. His face was streaked with coal and his hands were completely black, but he seemed to enjoy his work.

When it was time to light a fire, we went down to the basement, filled a bucket with coal and carried it up to the first floor. When morning came, all that was left were ashes, which we used to spread on the sidewalk when there was snow or ice. Everyone on our block helped one another shovel snow, not just on the sidewalks but also out in the street. Things are different nowadays. If you ask me, people are not as helpful as they used to be, and it's hard to find the sense of camaraderie that I remember from my childhood.

The house was almost new when we moved in. My parents bought it from one of my father's colleagues, who had unfortunately been forced to sell it after his divorce. Back in the 1950s, the police force had the highest rate of divorce in Denmark. I don't know if being married to a police officer was harder then than it is now, but it certainly wasn't a guarantee for a successful marriage.

In any case, a year later, when my sister and I were about three-

and-a-half years old, my parents also got divorced. Anne and I stayed with our mother in the house in Lyngby, while my father moved to nearby Virum to live with a widow whose pilot husband had been killed in a plane crash. To add insult to injury, the woman had been my mother's best friend!

My mother was deeply unhappy and often cried for hours on end. Fortunately, my father's aunt supported her in every way, reminding my mother that it wasn't worth crying over a man who had left not only her, but also his two young daughters.

So then there were just the three of us in our big house. We didn't feel lonely, however, because we had such good neighbors. The house was in a cul-de-sac, inhabited mostly by families with children. The children all played in the street, and the fact that Anne and I were deaf wasn't a problem. By gesturing, we were able to communicate well enough with the other children for us to be able to play together. Children don't need many words.

Since we didn't have televisions or Playstations to entertain us, we invented our own games. One of our favorites was a re-enactment of the Olympics.

We made our own "torch" by filling a tin can with coal and attaching it to a pole. Our makeshift torch worked every bit as well as the real thing. My mother, watching us through the kitchen window, laughed in delight at the sight of us conducting the opening ceremony with such pomp and circumstance. Our Olympics had various sports, such as running and long jump, as well as all kinds of ball games. We also played circus, hide-and-seek and tag.

With close playmates like these, we couldn't have wished for a better childhood.

When our street celebrated its fiftieth anniversary in 1995, almost all of our old playmates came. Meeting them again as adults was an overwhelming experience. Anne and I are still grateful that they accepted us as deaf children and unhesitatingly included us in their games.

Even though we grew up as deaf children with a single parent, Anne and I had a good childhood, owing to some extent to our good neighbors, but largely to my maternal grandparents, who played no small part in our upbringing.

2. My grandparents

A small black-and-white photo from 1911 shows my maternal grandmother and grandfather as newlyweds. My grandmother, Sofie, is wearing a black wedding gown, which was in vogue at the time. Her halo of hair was in the so-called Gibson style, which had originated in the U.S. in the 1890s. She is seated in a chair, while my grandfather, Frederik, sporting a thick mustache, is standing proudly by her side. I treasure this lovely portrait of my grandparents, who were such an important part of my childhood.

When they met, Frederik was already a skilled bricklayer, who built many houses in Roskilde during his lifetime. He had been summoned to the home of a wealthy family who wanted to build an extension to their already imposing residence. Coffee was served by a charming housemaid named Sofie. Frederik fell for her at once, and the feeling must have been mutual, because they were married not long afterwards.

Frederik built them a large yellow house by Roskilde Fjord. They had two children, my Uncle Gerhard, and later, in 1915, my mother, Anne-Margrethe, called Grethe.

My sister and I enjoyed many good times in my grandparents' yellow house while we were growing up. My mother took us to

Wedding photo of my grandparents,
Frederik and Sofie Andersen in 1911

The groom, with a handlebar moustache and hair parted on the left, is standing in a black frock coat and waistcoat with a white high-neck collar and bow tie. His left arm rests on the back of his bride, who is seated at a small round table. She is wearing a high-neck dark silk wedding gown with dark lace on bodice and underarms. Her long dark hair is fashioned into a halo edging her face. She is holding an open book in her left hand on the table.

Indoor double studio portrait. Roskilde, 1911.

stay with them every other weekend, so that she could have some time to herself. My grandparents also looked after Anne and me during school holidays and part of the summer vacation, since my mother had to work. We often slept in the attic with our grandmother. During the summertime, we kept the attic window – a square window with iron bars – open at night so that a cool breeze from Roskilde Fjord wafted into the room. We slept soundly, even though our comforters were stuffed with chicken feathers that occasionally pricked us through the coverlet.

One morning I got out of bed and admired the brilliant view of Roskilde Fjord and the cathedral, a picture I remember clearly to this day. My mother told me once that when she was growing up, she always fell asleep to the sound of the waves in the fjord, which she could hear through the open window. When she moved away from home, she had trouble falling asleep, because she was no longer rocked gently by the familiar sound. Although I will never be able to understand that sound, nor its loss, when I looked at the motion of the waves, I felt that I was able to "see" the sound my mother had been able to hear.

There was a shelf in the attic with a wash bowl and pitcher, and every morning my grandmother went downstairs to get hot water so that Anne and I could wash our hands and face. While there was a bathroom with a large bathtub in the basement, Anne and I were not allowed to bathe in it when we were little. Instead, they used to put us in a zinc washtub in the back yard.

We brushed our teeth in the kitchen, which was lit by a single

light bulb in a metal shade. Our grandfather liked to tease us by taking out his dentures and showing us his toothless mouth.

The kitchen sink was made of white tiles with a metal rim, and there was only one faucet – for cold water. Hot water had to be heated over a gas flame. I remember seeing a picture of my mother when she was young, standing over the gas stove and boiling water. My grandparents were among the first people in Roskilde to own a gas stove, and, in fact a picture of ours was used in an advertising campaign. There was also a pantry off the kitchen, where we kept the food and the kitchenware, much of it a popular series in blue enamel.

My grandmother could often be found waiting on the sidewalk with a basket over her arm. On certain days the butcher's van came by with meat and sausages. On other days it was the cheese monger or various other merchants. My grandmother was able to buy almost everything she needed from the curb – even ice cream, which stayed frozen for a while in its packaging. Since my grandparents didn't have a refrigerator, this was a welcome alternative. After all, the one grocery shop, where they could buy flour, sugar, coffee, and other staples not sold by the visiting merchants, was a good two miles away.

In the dining room there was an old-fashioned wall phone, which my grandmother used occasionally to order groceries that were then delivered to their door. It had a crank on one side and a receiver on the other, with two round bells and mouthpiece on the front.

While most people know that Alexander Graham Bell invented the telephone in 1876 – with some of the credit later given to the Italian Antonio Meucci – not too many people know that Bell's wife was deaf and that Bell himself taught deaf children. In developing the telephone, he had actually hoped to facilitate communication for deaf people.

In the middle of the dining room was a large table with six finely carved high-backed chairs, and pushed against the wall, a matching sideboard. The plates on its shelves were arranged according to size, while the silverware in the drawers was kept in protective flannel bags.

There was also an ottoman in the dining room, where my grandfather liked to sit and look at the garden through the large window. On the windowsill were various potted plants, which my grandmother tended carefully. By looking through the garden gate, my grandfather could also keep an eye on the people and cars passing by. The postman came twice a day, bringing mail in the morning and the daily Roskilde newspaper in the afternoon. I often wondered how my grandfather could waste so much time watching life go by on the street, but later on I realized that he'd also been listening to the radio. I eventually discovered as well that I could tell whether the radio was on by touching it with my finger to sense vibrations.

My grandparents had a large vegetable garden. There were several rows of potatoes and strawberries, with slender stalks of chives lining the path that ran down the middle, as well as apple and pear

trees and elderberry bushes, which blossomed next to a small red shed, where my grandfather frequently took an afternoon nap. From time to time I helped my grandmother pick berries and do various other garden chores. Like my parents, my grandparents didn't know sign language, and yet they always managed to let me know what they wanted me to do, and I understood what they were trying to tell me. Language wasn't really necessary.

My grandmother made cordial from the white elderberry flowers, and canned pears in sugared water in tall glass jars, which she kept stored on shelves in the basement. During the winter she would bring up one of the jars, so that on Sundays we could have sweet pears topped with whipped cream.

When it got too hot, my grandfather and I used to walk to a small rise at the bottom of the garden and sit on a yellow bench shaded by tall trees. Here we could enjoy the view of the vegetable garden and watch my grandmother pick strawberries or chives. We didn't talk, but just enjoyed sitting there together.

I have sometimes wondered what my grandfather thought about having two deaf grandchildren. My speculations will go unanswered, but one thing is certain: I always felt secure in his company, because he understood how to be himself and treated me as he would have treated any other grandchild.

Sofie and Frederik did manage to celebrate their golden wedding anniversary, but by that time age had already taken its toll on my grandfather. He died in 1963 at the age of eighty-two after having been nursed at home for many years by Sofie.

Widowhood was difficult for my grandmother. She disliked being alone in her large house, so she bought a dog for company. I don't remember what kind it was, but it was small, dark and mottled with splayed legs, pointed ears and huge eyes. Despite its size, it was an amazing watchdog.

One day when my grandmother was eighty-two, the doctor came to the house to check on her health. After examining her, he recommended that she move to a nursing home. She was so incensed that she ordered him out of the house!

Fortunately, her son, my uncle Gerhard, lived across the street. One day in August 1970, shortly after the doctor's memorable visit, Gerhard found her lying unconscious on the floor of her house. An ambulance rushed her to the hospital, where she died three days later without having regained consciousness.

During my grandmother's funeral at Himmelev Church, I cried bitterly. My dark mood was worsened by the absence of a sign language interpreter at the funeral, which meant that I was unable to follow the minister's speech or understand what the rest of the family said. I felt completely shut off and alone.

My grandparents' house – the house my grandfather had built at the beginning of their life together – was eventually sold. It lives on in my memory, however, brightening up the street with its yellow exterior.

The death of my grandparents was a great loss, but I will always remember them with warmth and gratitude. Even though we didn't have a common language in which to communicate,

I never doubted their love, and they deserve a great deal of the credit for giving my sister and me a warm and happy childhood.

3. My parents

My parents, Svend Valdemar and Anne-Margrethe, were married in Roskilde in 1940, shortly after the start of World War II and Germany's invasion of Denmark. My father had been a police officer in Roskilde, but when he was offered a job with the Aarhus police, my parents moved to Aarhus into an apartment in the city's first concrete high-rise. The yellow apartment complex still stands today, although my mother used to say that the walls were so thin you could hear the neighbors flip a light switch.

One day my parents came home to find to their alarm that someone had broken in and ransacked the apartment. They quickly realized that it must have been the work of the German secret police, better known as the Gestapo. During the German occupation, numerous Danish policemen were arrested by the Gestapo, because they refused to assist them in their search for members of the resistance. Since police officers captured by the Gestapo risked being deported to concentration camps in Germany, my parents felt that their only option was to leave the country. On December 21, 1943, they fled to Sweden in a fishing boat and arrived two days later in Sätra Brunn, near Stockholm.

In a postcard they sent to their family in Roskilde in January 1944, my parents wrote that life was good in their new surround-

Portrait of my mother

Portrait study of Kirsten's mother, Anne Margrethe Andersen. She is photographed from the side with her sweet smiling face turned toward the photographer. Her dark hair is short with a side part and soft permanented curls. She is wearing a light silk blouse with tiny buttons up the front and a dark jacket with a long lapel.

Indoor b/w studio photograph. Roskilde, 1938.

ings. They were housed satisfactorily, had made new friends, my father liked his work and my mother had learned to crochet.

Although they moved a number of times during their stay in Sweden, they were at least safe and in good spirits. In March 1944, they wrote to the family again saying that they had moved to a nice little apartment in Jönköping, that they enjoyed cooking and that they went cross-country skiing whenever there was enough snow.

My father also became a member of the Danish Brigade, which had been formed in 1943 by Danish military personnel, policemen and resistance fighters, who like my parents had fled to Sweden. My father once showed me his armband, the so-called "freedom fighters armband" in pale blue, red and white.

In August 1944, my parents were relocated once again, this time to the police barracks in Malmø. Based on their reports to family in Roskilde, they seemed to be thriving in Sweden, and yet it must have been a difficult time. My mother's passport is stamped with numerous residence permits from Malmø's Wartime Board, the Swedish Immigration Commission and the Swedish Police Authority in Malmø, to which she had to apply to extend her stay. The final stamp in her passport, noting her departure from the Malmø Ferry Terminal, is dated May 11, 1945. Germany had capitulated and their exile in Sweden had come to an end.

As mentioned earlier, Anne and I were born in 1947 and our parents were divorced in 1950, after which we continued to live with our mother in Lyngby. When we reached pre-school age, a

Portrait of my father as a soldier

Portrait study of Svend Valdemar Malmbak in uniform with a single-breasted jacket and cap with a flat circular top and shiny visor and cockade. The uniform is without insignias or decorations. Malmbak is seated and holds his gloves in his right hand. He looks solemnly at the photographer.

Indoor studio b/w photograph. Copenhagen, 1936.

decision had to be made about which pre-school we should go to. There was in fact a pre-school for deaf children in Copenhagen, but my mother couldn't manage to bring us to the city and get to work on time every morning, so instead she decided to enroll us in a pre-school for hearing children closer to home.

Every morning she wheeled her heavy black bicycle to the front of the house and lifted one of us on the saddle and the other on the cargo rack. Then she walked the bike with us on it all the way to the pre-school next to the train station. After delivering us, she biked to a lingerie company, which manufactured bright-pink bras, garter belts and corsets, where she worked in the office. Needless to say, the employees were all women.

My mother's job consisted of doing the bookkeeping, as well as taking orders over the phone and keeping track of packages. At the end of the day, she bicycled back to the pre-school to pick up Anne and me, and, as in the morning, perched us on the bike and walked us home. I can't help thinking that my mother was a strong woman in many ways.

Anne and I were the only deaf children in the pre-school, but just as with the children who lived on our street, we had no trouble playing with our hearing classmates. Of course, our teacher didn't know sign language, but she was able to communicate with us by using mime and gestures. A photograph taken at that time shows Anne and me sitting on either side of our teacher, while she points to the illustrations in a children's book, so that we can follow the story she's reading to the other children.

Shortly before Christmas, I had an accident in the playground: I fell off the seesaw, hit my head and was knocked unconscious. When I came to, I was lying on a gurney being wheeled into an ambulance. The paramedic gave me a big smile when he saw that I was awake.

As it turned out, I had a concussion and had to spend Christmas in the hospital, though it was all so new and exciting that I didn't feel in the least sorry for myself. The hospital had a gigantic Christmas tree, larger than any I'd ever seen before, and a porter kindly carried me around it so that I could admire the tree from every angle.

When I was finally released from the hospital, my mother took me to my grandparents in Roskilde for a delayed Christmas Eve celebration. Anne was already there, and I've never forgotten the warm welcome I got when my grandparents opened the red front door in their bright yellow house.

Laundry day was always a big event in our house in Lyngby. We had a large coal-fired kettle in the basement in which my mother boiled the laundry. The air would be filled with the delightful scent of soap flakes as she stirred the steaming kettle with a wooden paddle, then scrubbed each piece of laundry on a washboard to remove any stains. I watched in fascination as my mother did the laundry, though it must have taken a lot of energy to do each load.

The introduction of washing machines in the 1960s certainly revolutionized this time-consuming task. The laundry kettle went out the door when a laundromat came to our neighborhood. Dur-

Problem solving

Anne and Kirsten are sitting next to each other in their kindergarten, the wall behind them decorated with children's art. As always, the twins are dressed alike, this time in long-sleeve tops and plaid suspender skirts. They have the same rather short haircut parted on the right side. Anne is looking pleased at having finished her puzzle, and is watching Kirsten still ordering a pile of small paper squares.

Brown-tinted photo, kindergarten, Gladsaxe, 1951. Photographer unknown.

ing the same era, coal stoves were being replaced by oil stoves, which meant that a brand-new oil tank took the place of our old coal burner. My father re-did the basement, transforming the part that had previously been used to store coal into a party room.

After ten years of being divorced, my parents remarried again in 1960. After another ten years, they divorced again in 1970. I asked my mother once what was going to happen in 1980, but she scolded me for being impertinent. As it turned out, my parents didn't get together again. My mother remained single from 1970 until her death in 1997.

My mother loved working in the garden. She had many rose bushes, and to discourage aphids, she dug banana peels and coffee grounds into the soil around the roots. She also enjoyed walking in the woods, but as she grew older the walks became too tiring. One day the neighbors trooped into the garden with their arms full of light-green beech branches.

"When you can no longer come to the woods," they told my mother, "the woods will have to come to you."

One day in 1997, my mother was so ill that she was taken to the hospital, where she stayed for a long time. Her friends and neighbors took turns visiting.

Before she died, my mother had decided the funeral service to be held in the Church for the Deaf at Frederiksberg performed by a (hearing) minister in sign language as a special consideration for Anne and me. The service was also simultaneously spoken in Danish by an interpreter for hearing congregants.

Anne and Kirsten being tutored by their mother in their living room in Frederiksberg

The girls are wearing identical dresses with a double row of buttons down the front. They are seated at a coffee table with ceramic tiles. Their hair is softly curled and they are seated next to each other on an upholstered sofa. Their mother is not visible, but Kirsten seems to be proud to be responding correctly. Perhaps her expectant smile means she is hoping to be praised. In contrast, Anne has her chin resting on her hand, staring at the photographer with a somewhat disgruntled expression.

B/W snapshot, presumably taken by their father. Frederiksberg, 1951.

Anne and Kirsten's mother teaching the girls at home in the living room

The twins' mother has dark brown hair with a side part. She is wearing a checked dress and is seated on the floor at a low coffee table with ceramic tiles (also shown in the previous picture). She is at eye-height with the girls and interacting by showing them different pictures on the table. The girls are seated on low wooden chairs on the opposite side of the table and eagerly responding and communicating with their mother.

The girls are wearing short-sleeve tops and plaid suspender skirts. The room includes a radio, a desk with many small drawers, and an upholstered armchair.

B/W snapshot, presumably taken by their father. Frederiksberg, 1952.

My sister and I with our teacher at Stengaard Preschool

Kirsten and her twin sister Anne stand on either side of their teacher at Stengaard Preschool. The teacher has dark hair and is wearing a white smock. She is seated with one arm around each twin. All three are smiling at the photographer. The girls look alike with their blond hair and identical solid-color dresses with white piping. Anne, right, is also wearing a buttoned wool cardigan sweater.

B/W indoor photograph at Stengaarden Kindergarden, Gladsaxe, 1953.

My sister Anne and I as school girls

Anne and Kirsten on a sunny day. Wearing identical plaid, pleated suspender skirts and soft white short-sleeve blouses, they have white ribbons in their short blond hair. Anne is looking at the photographer, while Kirsten is looking off to the side.

Outdoor b/w photograph, Virum, 1955. Photographer: presumably the twins' father during a visit with him.

4. School for the deaf

In 1954, Anne and I started at the State Boarding School for the Deaf in Copenhagen. The school was nestled between The British Embassy and the Institute for the Blind and Partially Sighted. Today it's an ordinary public school with a small department for deaf and hearing-impaired pupils. Cochlear implants (CI), which give children with congenital deafness a good chance to develop sound and speech, have reduced the need for schools for the deaf.

Having served as a school for deaf children since 1839, it consists of the original, yellow-washed building as well as a white addition designed by Sven Eske Kristensen, which was built in 1968. The neighboring Institute for the Blind and Partially Sighted was designed by F. Meldahl and built in 1858. Today that building is under an historic preservation order, while the school for the deaf's yellow building, a superior example of its kind, is also a protected historical building

On the first day of school, Anne and I wore matching dresses made by our mother, who had come with us. We must have made quite an impression, as some of my classmates told me later that they've never forgotten their first sight of the two of us.

First-graders were divided into four classes. Unfortunately, my sister and I were not assigned to the same one. I was in Class A

and Anne in Class B, with Mr. C.M. Larsen, whose son was deaf, as her teacher.

Class E was a remedial class with Inge Larsen as the teacher. Miss Larsen was a popular teacher, because she used clear, beautiful sign language that her pupils loved. She was also the head of the local division of the Girl Scouts and often had meetings with their protector Queen Ingrid, the wife of reigning King Frederik IX.

Our school had the same number of first-graders as typical public schools did, and yet we had to be divided into four smaller classes. This was because we had to sit in a semi-circle in front of the teacher in order to follow the lesson. Therefore, the remedial class had only two pupils, Class C had four, and Anne's class as well as mine had six. Two girls from the Faroe Islands, Oddvør Olsen and Susanna Restorff, were in my class. Since there were no schools for deaf children in the Faroe Islands at the time, deaf children had to go to school in Denmark. The pupils sailed from Thorshavn, the capital of the Faroes, then to Scotland, and finally to Esbjerg, in Jutland. They were very young, I thought, to be leaving home for such a long time.

In order to accommodate the children from the Faroe Islands, as well as those from other parts of Denmark, our school was a boarding school. The boarders slept in a dormitory in the attic and had two foster mothers, Rano and Margit. The non-boarders arrived every day by train or tram.

One time a few boys from the school went into town and sauntered down the street in front of a tram. Although the tram driver

Enjoying ice cream cones on a sunny day at Lyngby Lake

Kirsten, Anne and their mother are seated at a wooden picnic table. Kirsten is wearing glasses and holding the cone in her left hand. Anne and their mother are both right-handed. All three are nicely dressed in light summer clothes, the girls in matching sleeveless dresses with a broad collar. Just behind them is a small harbour with boats to rent. In the distance are a small island with trees and small boats sailing in the fine Scandinavian summer weather.

B/W snapshot, likely taken by their father. Lyngby, July, 1954.

rang his bell repeatedly, it was useless because the boys couldn't hear it. Passersby stared at the boys in confusion, while the tram passengers complained about the delay. I don't know why the boys did anything so foolish, but perhaps it was a form of protest.

Trams were considered inflexible in traffic and were gradually being replaced by buses. Copenhagen was the last city to retire its trams, and operations stopped for good in 1972. I remember reading in the newspaper that the old tram cars were sold to Egypt. I found it reassuring to know that they were being used somewhere else rather than simply being scrapped.

Our school actually bought one of the retired trams. It was delivered by crane one day when we were in the middle of class. We all rushed to the windows to see what was happening. Three men spent several hours maneuvering the tram into the designated spot on the grass next to the playground, where it looked somewhat out of place. Why the school decided to buy the tram is beyond me, since we were never allowed to play in it, though we were dying to. We were only allowed to peer inside when accompanied by a member of the recreation staff after school.

At that time, our teacher was Jens Lundberg. He used very little sign language in his teaching, preferring instead to write on the blackboard. To begin with we were ordered to copy his written sentences into our workbooks and to indicate the nouns with an X and the verbs with an O. Since this was my first encounter with sign language, I was relieved that we were using so much written language. However, I was left-handed, which angered Mr. Lundberg. He insisted that I write with my right hand, even though I found it tiresome and difficult. I could write much faster with my left, so whenever Mr. Lundberg turned his back, I hurriedly switched my pencil to the other hand. One day he saw what I was doing and rapped me on the knuckles. After a while he relented, thank goodness, and allowed me to write left-handed.

Part of our schedule was devoted to speech exercise, called articulation, which was extremely unpopular with the pupils. We would be called one at a time into a small room where the articulation teacher would be sitting at a desk. There was a mirror on the table, so that you could sit next to the teacher and see your own reflection while following her instructions in the mirror. As you tried to speak, the teacher would press a wooden stick on your tongue to get you to understand what it should be doing when you were trying to pronounce certain letters. I found it unpleasant and unnatural.

Most of the pupils hated speech exercises. Using our tongues and bending them into strange shapes felt unnatural when we couldn't hear the sounds being made. We preferred using silent sign language, a mode of communication that came naturally to us. In those days, we were considered deaf and dumb, which is not true. In fact, we can scream our heads off! But we prefer not to use our voices, because it's hard for us to control them, and hearing people sometimes find our speaking voices strange.

Back then we weren't given a choice in the classroom. During recess, however, we were free to use our silent sign language,

which was a relief, since we found it to be the easiest and most natural form of communication. Actually, I learned most of my sign language during recess and after school when I was playing with my sister and classmates. In the classroom, we primarily used the MHS system, which is not an independent language like sign language, but a support system using various hand and finger positions plus lip reading to indicate some of the sounds of spoken language. [Phonetic hand signs, which can be compared to R. Orin Cornett's Cued Speech.] At that time teaching was concentrated on enabling the deaf to adapt as much as possible to the hearing world. While Anne and I attended the School for the Deaf, my mother also learned MHS, which is how the three of us subsequently communicated with each other, although Anne and I always used sign language when we were alone.

I had always assumed that most of the teachers at the School for the Deaf were satisfied with my performance, as I was good at writing and arithmetic. While that was mostly true, I was thrown for a loop recently when I came across a carved wooden chest that had belonged to my mother. In it she had kept all my old report cards from school. Several of my teachers had commented that my speech was unsatisfactory. Hardly surprising, I thought, shaking my head, though I hadn't been the only deaf pupil who had to struggle with speech. It had been a problem for many of us.

While I'd admittedly not been equally enthusiastic about every aspect of learning, I'd had many good experiences at school. Three of them in particular have stayed in my mind.

One day in the middle of a lesson, a nattily attired ship's captain suddenly appeared in our classroom. All eyes were immediately focused on him, and while I was wondering who that handsome man might be and what he was doing here, Oddvør, one of the two girls from the Faroe Islands, jumped up and ran over to him. The man turned out to be her father. They had not seen each other for ages since he'd been sailing around the world. Seeing them be reunited was so touching that I've never forgotten it.

Another event that remains etched in my memory occurred in September 1962. The Russian cosmonaut Yuri Gagarin, who had become the first man in space the year before, was visiting the Russian embassy, which was close to our school. We joined the crowd of spectators gathered outside the embassy, hoping to get a glimpse of the world-famous cosmonaut. Not only did he make an impressive entrance in an open convertible, he was handsome to boot. Oddvør actually dared to touch him, a feat she never stopped bragging about. Unfortunately, he died six years later, a mere thirty-four years old, during a training mission.

The third event took place when our class was invited to a soccer game, although I have no idea which clubs were playing. What made the day so memorable for us was that we were allowed to watch Knud Lundberg, a former player and sports journalist, at work. Our teacher Jens Lundberg was his brother, which is how this opportunity came about. First we watched the game, then we followed Knud to his newspaper office to see what it was like to write and edit a newspaper. Quite an experience.

I had three different classroom teachers while I attended the School for the Deaf: the first was Mr. Lundberg. Next was Mr. Ditlev, who always put gobs of pomade on his hair and whose name sign was "Got it?", since that was one of his favorite expressions. He was later transferred to the Faroe Islands to help establish a school for children who were deaf or otherwise handicapped.

Our last classroom teacher was Mr. Hagedorn, with the name sign "Lotsa hair". He was the driver of the minibus that took the whole class to Germany after we had all been confirmed. We stayed in various youth hostels along the Rhine. In one of them I saw a group of nuns, which I found very odd.

We were ninth-graders at the time of the trip and almost fifteen years old, unlike hearing children, who are typically confirmed at age thirteen. We were confirmed in the Church of the Deaf in Copenhagen, which was designed to enable the whole congregation to see the minister. The floor slopes gently down from the entrance to the altar, and the pews are arranged in tiers as in an amphitheater. During the ceremony, the confirmation candidates were not seated in the pews, but rather on chairs in a semi-circle in front of the altar, so that we could follow the minister's words in sign language.

The principal of our school, Asger Holm, gave each of us a special confirmation gift: a thick green dictionary that he had written himself, filled with simple definitions that were easy for us to understand. He had also taught many of our parents MHS, and I was very pleased that my mother had taken his class. When Anne and

I were younger, she'd been too tired, as a full-time-working single mom, to learn either sign language or MHS, but now she finally had enough energy to devote to it. Even though we'd managed well without language, I valued my mother's efforts, which made for better communication between her and her daughters.

Graduating from the ninth grade in 1963 without having taken any exams or earned any kind of certificate felt odd. Luckily Anne and I were able to attend Denmark's continuation school for the deaf, which I will write about in a later chapter.

5. Deaf Girl Scouts

As school-girls, we loved going to Girl Scout meetings, which were held in the school's attic in the evening. We learned to tie knots, recognize the leaves of many trees, send and receive Morse code and much more. We have our leaders Elly Noormagi and Inge Larsen to thank for deciding that deafness was not an obstacle to our becoming Girl Scouts.

Our first Girl Scout camp was held in East Jutland, and in 1962 we camped on the island of Funen. We had permission to set up camp on a field belonging to the parents of Knud Søndergaard, the deaf chairman of the Danish Deaf Association, and later the director of the secretariat. Over the years, he also held other deaf-related posts in Denmark and internationally, and made a major contribution to improving conditions for deaf people.

Instead of sleeping on air mattresses, we collected straw from the farm and filled great big sacks with the sweet-smelling stuff. After our first night at the farm, we woke to the unexpected sight of a herd of cows ringing our camp. Perhaps they had never seen a group of Girl Scouts before and wondered what we were doing there. Every morning we did a few stretching exercises to work out the kinks, and the cows gradually lost interest in us.

One day a crew from the Danish Deaf Film Company came by

to shoot some scenes for a movie. Knud Søndergaard had a role in the film, and we were royally entertained by watching the takes.

One of our best scouting experiences was the Girl Scout fifty-year jamboree held on Funen in July 1960. Girl Scouts from all over the world headed for the island, and while the owners of Brahetrolleborg Castle had generously offered to lend us their grounds, there were simply too many campers for the space. The organizers wanted to keep the celebration on Funen, and managed to establish seven camps on the island on land belonging to various manor houses: Erholm, Hverringe, Risinge, Tybrind, Sandagergård and Juelsberg near Nyborg, in addition to Brahetrolleborg Castle.

Queen Ingrid took part in the opening ceremony, greeting the crowd of scouts from the stage set up for the occasion, before starting on a tour of the six other camps. Since her goal was to visit all seven camps in a single day, she was flown from one to another by helicopter. Our motto was "Be prepared", and that we were as we awaited the queen's visit to our camp. While we normally wore light blue uniforms in summer, on this special occasion we were lined up proudly in our more formal dark-blue uniforms when the queen's helicopter landed in our camp.

As I mentioned earlier, our teacher and scout guide Inge Larsen knew Queen Ingrid well. At one point in the queen's visit to our camp, Miss Larsen whispered in the queen's ear that one of the scouts was homesick. The queen made a point of talking to the sad little scout, which cheered her up no end.

The queen carefully observed how we had set up camp. We had fashioned our own kitchen table, with a hole for the wash basin, where we could stand and do the dishes. Next to the table we had suspended a double rope on which to hang various utensils. Queen Ingrid admired our handiwork and praised our ingenuity. Girl Scout camp helped build our confidence and strengthen the social skills needed to cooperate on practical tasks.

Lady Baden-Powell, the first Chief Guide for Britain, also paid us a visit during the jamboree, which we considered a great honor. She was the widow of Lord Baden-Powell, a Boer War hero and founder of the world scouting movement in 1908.

Girl Scout camp also provided the backdrop for the first signs that I was having problems with my sight, though not on a conscious level. When I had to make my way to the toilet in the evening or at night, I constantly tripped over the guy lines securing tents. While it is admittedly more difficult to see at night, eyes generally adjust to darkness after a few minutes. However, I was hopelessly night blind, and it was not until many years later that I learned that night blindness is a symptom of the disease that gradually robbed me of most of my sight. But more about that later.

Strange as it might seem today, back in the 1960s, we travelled to scouting events mostly by ferry and train. The train doors were solid and heavy, and once the passengers were on board, an attendant would go from door to door to lock them manually. Only now do I realize how much work that must have been. Once the train was moving, the conductor, very official in a black uniform,

came past each passenger to punch a hole in our small brown tickets. Scouts were given a group discount. Passenger cars were divided into compartments, and we usually sat eight to a compartment. We opened the window to get some fresh air, as there was no other form of ventilation. Trains ran slower than they do today, stopping at every station. Upon arrival at each station, we peered through the open window to follow what was happening on the platform.

To get to Jutland, we first took the train to Kalundborg Harbor, where we got off with our backpacks and suitcases and walked to the ferry. The ferry crossing took three hours. After our arrival at Aarhus Harbor, we had to make our way to the train station, again struggling with our heavy brown suitcases. The other passengers all had the same problem, and stairs were a real trial. Of course, this was before someone had the bright idea of putting wheels on suitcases.

To get to the island of Funen, we crossed a body of water called the Great Belt from Korsør to Nyborg, though this time the train was guided onto a train ferry. There were a huge number of train tracks at the old Korsør Station, whereas today there are only three, all of which lead to the Great Belt tunnel, which opened in 1997.

Those ferry trips were delightful. We used to sit on the deck to feel the fresh sea air. Despite the hours of travel and the primitive living conditions in the Scout camps, we loved being outside in all kinds of weather.

On the way to Girl Scout camp by train: Inge Thomsen, Anita Christensen, Eva Ruben and Anne Malmbak

Four 13-14-year-old deaf Girls Scouts wave goodbye from an open window in a wooden-sided train car on their way to summer camp. The girls are wearing identical dark blue uniforms, but have different haircuts and hair color ranging from blond to brunette. Anne is the only one with glasses.

Snapshot. Copenhagen Central Station, 1960. Photographer: Svend Malmbak

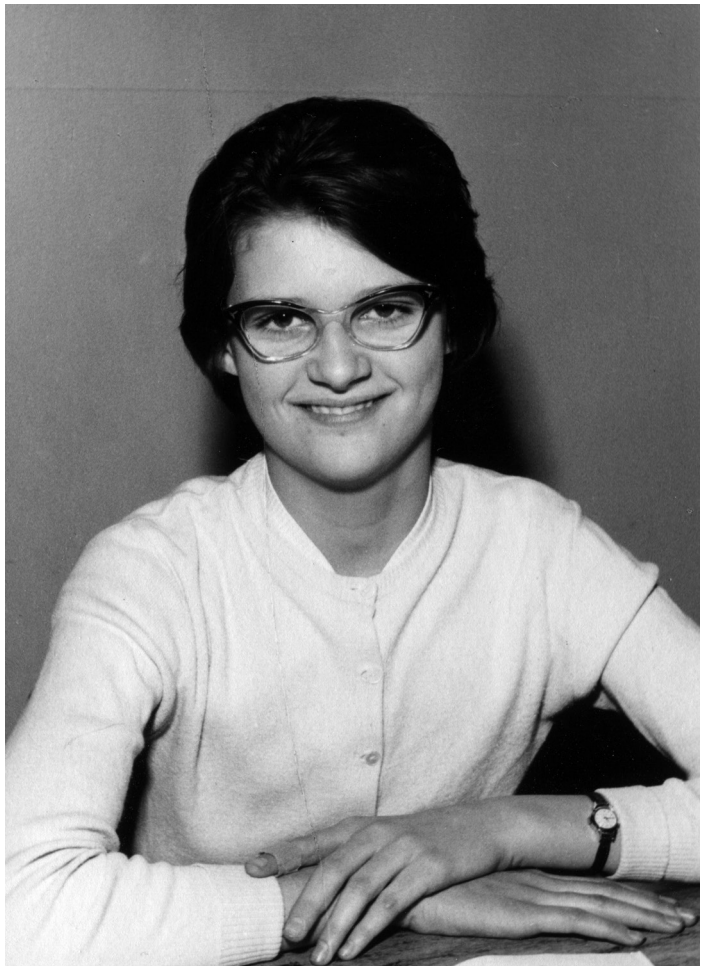
As I recall, we almost always had good weather during our summer trips. Either the weather has been more unstable here in the new millennium, or I simply remember the sunny days more vividly than I do the gray ones.

6. Nyborg School

Denmark's only school for deaf students after the ninth grade was located in Nyborg on the island of Funen. Called the State Continuation School for the Hearing Impaired and Deaf, it was more commonly known as Nyborg School. Assembled here were most of the deaf youth who had finished the ninth grade at one of the five schools for the deaf in Aalborg, Fredericia, Nyborg and Copenhagen, where there were two. Nyborg School had been established in 1891 as The Royal Deaf-Mute School in Nyborg, and originally served as a school for deaf and hearing-impaired children. In 1958 the school began expanding into a continuation school for deaf and hearing-impaired teenagers, and the lower grades were phased out completely in the mid-1960s.

Nyborg School is a handsome red-brick building surrounded by a lush park. A large lawn spreads from the old school building to the yellow-gated park entrance. Nyborg School held its centennial jubilee in 1991. Of course I attended the unforgettable party for both students and teachers that was held in a large tent erected on the lawn. Today the park is host to children's agricultural shows, summer funfairs and flea markets.

Most of us deaf youngsters were happy to continue our education at Nyborg School, where we made new friends from all over



Kirsten at her desk at the School for the Deaf, Kastelsvej

Official school photo of Kirsten seated at her desk with her hands folded in front of her. She has a wristwatch on her left arm and an open book in front of her. She is wearing a long-sleeve white blouse topped by a white knit buttoned vest. Her asymmetrical hairstyle partially covers her left forehead. She is wearing glasses and smiling warmly at the photographer.

School photo. Copenhagen, 1962.

the country. Although the dormitory had been opened officially the year before, not everything had been finished in time. Rumor had it that a bulldozer had roared its way beneath the windows during the opening speeches. Because construction was still going on when school started, the students had to make do with a few makeshift solutions, such as the use of bicycle inner tubes to drain the sinks until pipes could be installed. The kitchen was not ready either, which meant that students had to eat out in town for the first few weeks.

It was smooth sailing for us when we started a year later in 1963, because by then the new dormitory had been completed. It was designed as a yellow-brick multi-story building next to a cluster of smaller dwellings that housed doctors and other employees of Nyborg Hospital. We walked past the hospital on our way from the dorm to the school every day, a walk of about ten minutes each way.

Once again, my sister Anne and I were not in the same class. Anne took business courses, while I repeated the ninth grade in order to prepare for my exams, after which I could go on to the next level. I learned later that the principal, Mr. Højbjerg, and my homeroom teacher, Mr. Laurents, had discussed whether I should be allowed to continue on an academic track due to my failing grade in spelling. Mr. Laurents insisted that I should be allowed to persevere, for which I am extremely grateful.

In 1965 the first deaf class in Denmark took the tenth-grade equivalent exam at Nyborg School, which received wide press

coverage. The second class, including Asger Bergmann, author of the book: "Sign language – why not?", passed the exam the following year. Then it was my turn with the class of 1967. The class of 1978 was the last to take the exam, which was replaced by a new tenth-grade exam granting admission to ordinary high school.

My classmates at Nyborg School consisted of three girls, Anne Skov, Annette and Annegrethe, and one boy, Henry. A small class indeed, but none of the classes had more than five to seven pupils. The school had a total of seventy to eighty students up until the 1990s, when enrollment began to fall due to the growing popularity of cochlear implants.

We gave Mr. Laurents, our homeroom teacher, the name sign "Mr. Tall", because of his height. I found it difficult to follow his lessons, because he used MSH rather than sign language. Having to focus so intently on his MSH sometimes gave me a headache. When I told him I couldn't understand everything he was saying, he replied that I would before two weeks had gone by. It was discouraging to note that my classmates could follow him easily, but he was right: Eventually I did learn to understand him.

Mr. Jensen, our math teacher, was a gentle, patient man, and we felt very confident in his presence. His wife also worked at the school as our school nurse.

Our German teacher, Mrs. Lyngbo, was a kind woman who smiled a lot, even though teaching us German grammar couldn't have been easy.

Our English teacher was in fact our principal, Mr. Højbjerg.

His name sign, "Ear Wart", was certainly not flattering, but we signed our teachers according to their most prominent trait. He too used only MHS, even for English lessons.

Our gym teacher, whose last name I have forgotten, was Tove. In addition to gymnastics, we also played volleyball in our "sports hall", which didn't even have spectator seating. I was beginning to have problems with my eyes and had trouble following the ball in the air. I would later learn that I was born with a syndrome called Usher, which was not only responsible for my deafness, but was now taking its toll on my eyesight. At the time, however, neither I nor anyone else knew this. Some of my classmates complained that I was a poor volleyball player, but I just shrugged.

In fact, Usher Syndrome affects not only sight and hearing, but balance as well, so swimming became my preferred sport. You don't need a sense of balance to swim, not to mention that you can do it on your own, without having to be dependent on others. Unfortunately, Nyborg School did not have swimming facilities, which ruled out my best sports option.

Even though volleyball was not for me, it was very important to many of the other girls, who continued to play after our years at Nyborg School. They later joined a sports club, Døvania, for deaf people in Copenhagen, which also offered soccer, handball and table tennis.

We were taught history by Mr. Vestergård, also a wonderful teacher. He had been in a concentration camp during the war and subsequently suffered from poor health, including a persistent

cough. He had been a policeman like my father, but had been arrested by the Gestapo and deported to a German concentration camp. When his poor health kept him from resuming his work as a policeman, he became a teacher for the deaf.

I've been told that during World War II, Nyborg School was closed to students and used as a field hospital for wounded German soldiers. The conditions were reputedly very unsanitary. It's strange to think that the school also had a dark history.

Every morning when we arrived at school we headed to the assembly hall to start the day by singing. Yes, we deaf students were actually supposed to sing! Some of us were not so inclined and mimed the words instead to make it look as if we were joining in.

After the morning assembly, we went to our respective classrooms, coming together again at lunchtime to walk back to the dorm, where a hot meal, presided over by the principal and his wife, awaited us.

We had a bit of free time after school, and we girls often played soccer on the large lawn. I was always the goalie – by choice. Usher Syndrome put me at a disadvantage, as my peripheral vision had begun to shrink, making it difficult for me to follow what was happening on the field. Usually during a match, soccer players communicate by yelling back and forth, but of course we had to rely on hand signals. Since I couldn't see the others trying to signal me, I ended up in front of the goal, where it was easier to follow the action. The game was a lot more fun for me when I only had to keep my eye on the ball.

Our evenings were also organized, and for special occasions we converted the dining room into a party room or sometimes even a "theatre." For example, we had so-called brother and sister evenings, when the boys and the girls took turns putting on a show. The boys once did an imitation of the Beatles – without the music of course – but they were such wonderful mimics that we girls were crazy about them!

When it was the girls' turn, we usually put on a comedy, like the classic restaurant sketch in which the guest is unable to eat her soup because she doesn't have a spoon. The problem escalates into a heated discussion between the guest, the waiter and the cook. We threw ourselves completely into the production, including providing convincing costumes for the waiter and cook.

The inspiration for our theatricals was a direct result of the Danish Deaf Film Company's visit to the school for a film shoot. Our assembly hall was used to create a courtroom scene in which everyone in the school took part. A student named Torben played the judge in a traditional white wig, and my classmate Annegrethe played the accused. I was a courtroom spectator.

Some of us were so bitten by the theatrical bug that after we graduated we joined the Theater of the Deaf, which had been established in 1960. Since performances were held in the attic of a school, the theater was also known as "The Attic". More about that in a later chapter.

We always had a big party in the dining room before going home for the Christmas holidays. I look back in amazement at

the energy we poured into making decorations. To get us into the Christmas spirit, we used to string long rows of cotton balls in the windows to simulate snow and to create elaborate nativity scenes with a little doll representing the baby Jesus.

One day our homeroom teacher Mr. Laurents asked us to make some drawings or artifacts for an art show. The exhibition was set up in the dorm's basement, where we usually played table tennis. There was even a competition for the best submission, and all of us were particularly impressed by a pencil drawing that one of the boys had made. He had drawn a lively street scene so vivid it almost looked like a photograph. Much to everyone's surprise, however, I won the competition. My entry had been a simple charcoal drawing of a bottle I had found in the basement. Mr. Laurents explained his decision by saying that we had been charged with creating art, not a photocopy. So I guess we all learned something new about art!

When the weather was good, most of us kids biked out to Nyborg Beach to wade, swim and lie in the sun. My poor balance prevented me from biking, so I had to walk the long way to the beach, waving to the others as they whizzed past me. I didn't really mind the walk, and it was only later that I realized how much more fun it might have been on a tandem bike!

Dinners were always served in the dorm's dining hall. We had assigned seating, with six people to a table, and were rotated every so often so that we could sit with new people.

The dorm didn't have any laundry facilities, so we put our dirty

clothes into numbered bags, which were sent to a commercial laundry. A few days later we'd line up to collect our clean clothes.

There was a shoe-polishing room with a long black table that stretched from one end of the room to the other. We each had a drawer beneath the table, which was filled with shoe polish and brushes so we could polish our own shoes.

The bathrooms had two rows of eight sinks. Because they faced each other, you usually found yourself staring at someone else as you brushed your teeth. There was a shower room with three stalls. It goes without saying that there were separate facilities for boys and girls.

On the opposite side of the corridor, we girls also had a kitchenette, with a cupboard for tea and other items that did not need refrigeration. One day the two girls from the Faroe Islands, Oddvør and Susanna, who had also been my classmates in school, received a package from home containing dried mutton, which stank to high heaven. The girls loved this traditional "delicacy," but we could smell it all the way down the hall.

We liked having a girls' wing to ourselves, because we were able to socialize more easily in our free time. We often congregated in the hallway, though that was taboo. One evening a group of girls decided to go to Annegrethe's room at the end of the hall. We were standing around in our nightgowns when the teacher on duty, Miss Ludin, discovered us. She reprimanded Annegrethe for having encouraged us to break the rules, but it was really the rest of us who were to blame.

The dorm was divided into two wings, one for the girls and one for the boys. We could see the boys' wing from our own, though visits back and forth were strictly forbidden. The connecting doors were even kept locked. Despite these precautions, one boy and girl did manage to get together after school hours, and when the girl got pregnant, she was expelled, while the young man was not!

In 2011, the two wings were considered so outdated that they were torn down and replaced by small row houses designed for handicapped people. In fact, most of the dorm was demolished; only the wing with the kitchen, dining hall and assembly hall was left as part of the new housing complex. In 2013, the whole school was closed due to falling enrollment, and later converted into an ordinary Adult Education Center. It's sad for us former students to think that the place that was so important to us in our formative years no longer exists. I'm glad that at least the dining hall, where we had so much fun, is still standing.

After receiving our ninth-grade diplomas in 1964, we went on to the next level. It took us three years under the expert guidance of Mr. Laurents, but we finally graduated in 1967. Many of us continued our studies, learning to be technical assistants, which was all the rage then among students from Nyborg School. Since our curriculum had been aimed at further training at a technical school, many of the graduates went on to studies in Odense or Copenhagen.

My classmates Annegrethe and Anne Skov chose a different path and later worked as consultants for what was then called

the Center for Total Communication, which trained people to be sign language interpreters. Anette got a job as a receptionist at the Center for the Deaf, now known as CFD.

My sister Anne, who had taken business courses for two years, got a good job with the Hafnia insurance company, which had an office in Copenhagen close to the Danish Royal Theater.

One day when Anne was on her way home from work, she suddenly felt a tap on her shoulder. When she turned around, she was surprised to see Ove Sprogøe, one of Denmark's most iconic actors. Apparently she had dropped her gloves and he was returning them to her.

I'm happy that my sister had a good job with such good colleagues for so many years, and that my other friends were also able to find meaningful work.

We have Nyborg School to thank for that.

7. Swimming

In my first many schoolyears, we walked about thirty minutes to the municipal swimming pool for our required swimming lessons. One of our teachers was Ragnhild Hveger, a Danish sports legend who set several world records, won a silver medal at the 1936 Olympic Games in Berlin, and the European championship in 1938. Although her star faded during the war when she took up with a German soldier, you have to admit that we had a highly qualified swimming instructor!

In 1962, my last year at the school for the deaf, several of my classmates and I were invited to a major swimming meet in Hamburg. I remember leaving on a Thursday so we could take part in the entire event, which lasted several days, and we did quite well.

That experience encouraged me to join a sports club for the deaf that offered swimming, tennis and badminton. The club was founded in 1938 and renamed D.I. Ryvang in 1983, because both the tennis courts and the badminton hall were next to Ryvang Station. The club chairman was Torkild Frederiksen, who held the post for many years. His wife Erna Frederiksen, who had won seven Deaflympics medals, was named deaf sportswoman of the century in 2000. That same year, the club's swimming champion, John Meisner, also a Deaflympics medal-winner, was acclaimed

deaf sportsman of the year. Torkild Frederiksen died at the age of seventy-two in 1978, the same year the club celebrated its fortieth anniversary.

In late 1962, my club swimming team was invited to take part in a major swimming meet in Budapest. We were the only deaf team from Denmark to participate, as we were the only swimming club for deaf people in the country!

My parents were worried about sending me abroad, since I was only fifteen. The club's team managers came to my home to reassure my parents that they would look after me. My father was still skeptical, as the Cold War was at its height, and Hungary was a Communist country. Luckily, however, my parents eventually gave me the green light.

The other swimmers and I traveled to Budapest on a train that offered little in the way of comfort. The reclining seats in the passenger car were supposedly adjustable, but were so uncomfortable that it was almost impossible to get any sleep.

When we arrived in Budapest, we were astounded to see red stars – the symbol of the Communist party –everywhere. Red flowers had been planted in the shape of a star in the middle of a traffic circle, and even the pillows in our hotel had red stars! But we were so tired and so happy to finally be able to sleep in a real bed that we fell asleep at once, communist stars or not.

The next morning I woke in surprise to see my worried teammates peering down at me. Exhaustion had sent me into a deep sleep, and one of the girls had tried to wake me for some time.

She'd then called the other girls, who'd gathered anxiously around my bed, hoping I'd eventually wake up. They were greatly relieved when I finally opened my eyes.

The swimming meet went well and we had good weather, but there were a few bumps along the way. For example, the water in the swimming pool was pumped in directly from the Danube, which meant that it was filthy. The boys from our club were also shocked to find a woman cleaning their dressing rooms as well as the men's room. Apparently the Hungarians thought that cleaning was women's work.

Lise Lotte, Annelise, Kirsten B. and Annie were the other girls on my team. We did very well, winning a gold medal in the team race.

On the way home, the train stopped at the border between Hungary and Austria. We stared out the window at the many guards. There were no platforms, so the guards walked along the tracks, checking to see whether anyone was trying to escape from Hungary by hiding under a train. After a lengthy stop, we finally continued into Austria past the many barbed wire fences. Escape from Hungary to Austria looked downright impossible.

Before reaching the Danish border, we had bought so many miniature bottles of alcohol with attractive labels featuring a stag that we were way over the limit. John from our club solved our problem by putting all the bottles in a large plastic bag together with the Danish flag and pole that we had carried during the opening ceremony. Fortunately, the customs officials didn't inspect the

bag, perhaps because John carried his heavy burden with such a winning smile.

The next year, 1963, I started at the school for deaf students in Nyborg. We often went swimming at the beach in the early and late summer if the weather was good. The town of Nyborg didn't have a public swimming pool at the time, so it was fortunate that the school was located so near the water.

We used to swim alongside the beach's long pier as part of our training. Most of us were good swimmers, as swimming lessons had been obligatory in the school for the deaf. We also splashed each other and bobbed around in circles in the water. All those days spent at the beach helped us form friendships and build team spirit.

Now, however, my need for year-round training was becoming a problem. While swimming in the sea was fine in warm weather, it was far too cold during the winter. Fortunately, the school was able to overcome Nyborg's lack of a public swimming pool by arranging training for us in Svendborg. Once a week from 1963 to 1965, a van drove the swim team twenty miles to the swimming pool and back.

In 1965, when I was just seventeen, I was selected to participate in the World Games for the Deaf – now known as the Deaflympics – in Washington D.C. I'm still amazed that I was able to qualify with what little training we had: weekly during the winter and sporadically at the beach in warmer weather.

This golden opportunity posed something of a dilemma for

Training in Frederiksberg swimming pool, about 1979

Kirsten is practicing her crawl in the Frederiksberg swimming pool. She is wearing a bikini rather than a training suit. She is not wearing goggles or a swim cap, so we can see the middle part in her hair. She is looking backwards as if trying to catch sight of another swimmer. Two other women in swimsuits are standing in the pool at the side, which is faced in white tile.

Frederiksberg swimming pool, Copenhagen, 1979. Photographer: Annette Thrustrup (EVA, a monthly magazine for women).

me, as our class was planning a trip to Austria right about that time. Now that I had an important competition coming up, I didn't want to neglect my swim training. I confided to Mr. Laurents, my homeroom teacher, that I really wanted to be allowed to go home, where I'd be able to train every day. He suggested that I tell the principal I couldn't afford the trip to Austria. This was accepted as a valid excuse, and I did return home while my class was in Austria.

Being able to train every day – morning and evening in all kinds of weather – in a 50-meter outdoor pool was wonderful. When my classmates returned from Austria, naturally I asked them about the trip. To my surprise, they told me it was a good thing I'd stayed at home. Feeling hurt, I asked why and was reassured to hear them say it was because they'd gone on a real drinking spree! Although it certainly sounded as if they'd had fun, all that alcohol would not have done my condition any good. As a consolation prize, they had brought me a cowbell.

A few weeks before leaving for Washington D.C., a girl named Maggie came to live with my mother and me. Maggie's sport was the high jump. Since she lived in Jutland and her trainer, Svend Åge Larsen, lived in Copenhagen, she stayed with us in order to get in as much training as possible before we both left for the World Games.

In July 1965, Maggie and I and several other deaf athletes from Scandinavia headed for Washington D.C. We flew from Kastrup Airport in an aging prop plane that looked more like a troop carrier, and refueled in Iceland. When we stepped out of the plane in Washington D.C., we were hit with a blast of hot air: We had arrived in the middle of a heat wave!

We were housed at Gallaudet College, the world's only liberal arts college for deaf people. The female athletes were assigned to a dorm with no coolers or air-conditioners. Joining Maggie and me were two tennis players, Grethe and Kirsten. Our team manager had a room to herself. The male contingent was made up of swimmers, water polo players, tennis players and gymnasts.

We arrived in Washington about a week before the Games began in order to adjust to the climate and time change. To help us stay in top form during our stay, our team managers had brought rye bread, liver paste and other Danish staples not available in the U.S. We ate lunch at a small round table reserved for our exclusive use. It was located right next to the cafeteria, where stacks of white bread were being served. The athletes from other countries certainly didn't envy us our special treatment, since they thought our food looked strange.

On opening day, we all took part in the Parade of Nations, which mean standing for hours on end in the oppressive heat. How I wished we had on white lightweight uniforms, instead of our regulation gray skirts or slacks, white shirts, navy blue blazers, and gray caps. Some of the young men complained that the uniforms made us look working class .

One of our tennis players, Grethe, was red-haired and freckled, and her normally chalk-white legs had become sunburned. Her

strong will won her a bronze medal despite the heat. Even though I didn't win any medals, I was happy on her behalf, as we had become good sport friends.

All the Scandinavian participants are still in contact via Facebook, and we share wonderful memories of our participation in the 1965 World Games for the Deaf.

The trip home was quite eventful. We had been airborne for quite a while, when one of the engines caught fire. I clearly remember seeing the flames out the window. Maggie blamed the fire on the plane's age, and she may well have been right. Heavy fog ruled out an emergency landing in London, so the pilot turned the plane 180 degrees and headed back to New York. We were on pins and needles throughout the rest of the flight, and startled by the long line of fire engines awaiting us at the airport. The rescue team had certainly been prepared for the worst, but they were quickly able to put out the fire. The airline company put us up in a good hotel overnight and we left the next morning in a newer and nicer plane.

After my U.S. adventure I returned to Nyborg School. Unfortunately, our principal decided to put a stop to our winter swim training in Svendborg, since he felt that it made us too tired to pay attention to our studies. So for the last two years, I wasn't able to train during the winter. Even though I missed the training, we did pass our exams with good results.

Another exciting athletic opportunity awaited me in 1968. Knud Søndergaard, the chairman of the Danish Deaf Association,

challenged me to become the first deaf woman to set a world record in the 1500-meter freestyle. No time had yet been registered for that discipline for deaf women. The idea was not for me to take part in a meet, but to record my best time while swimming alone.

The fateful day was set for August 25, 1968 in Gladsaxe's sports center with a 50-meter outdoor pool. Three men, including Knud Søndergaard, stood by with a stopwatch. The official record would be the average of three trials. Since I wouldn't have been able to hear a starting pistol, the start signal was given by a flag. I was the only woman in the pool that day, but my swimming buddy, Leon Larsen, swam ahead of me in the adjoining lane in order to keep up the pressure.

My time was exactly twenty-eight minutes, which is not that fast, actually. But it was the first official time logged in the 1500-meter freestyle in the deaf sports world. I held the record for eight years before it was beaten. I'm proud that I was chosen to be the first deaf woman in the world to set the time for that discipline for generations of swimmers to come.

I also took part in the 1969 World Games for the Deaf in Belgrade, Yugoslavia. Though I didn't win any medals, Danish swimmer John Meisner won both gold and silver. At first the organizers were unable to find a Danish flag for the awards ceremony. Perhaps they hadn't counted on a Danish winner. In any case, a tiny, crumpled Danish flag was eventually located at the bottom of a box, though it looked pathetic when displayed alongside the huge unwrinkled flags of the other nations. Our time in Yugoslavia was

very different from our time in Washington D.C. four years earlier. The food was poor and many of us struggled with various intestinal bugs. After all, Yugoslavia was an impoverished country very much under Communist rule.

The next World Games for the Deaf were held in Malmø, Sweden in 1973. This time I attended as a spectator, since I was getting too old to compete at such a high level, not to mention that I was also heavily involved in several organizations, which took up a lot of my time. I had mixed feelings as I followed the opening ceremony from the grandstand, and yet I reminded myself that swimming had brought me great rewards and that I had given back as much as I could.

8. Technical school and my encounter with the job market

As I have mentioned, many of the students from Nyborg School went on to train as technical assistants. Once my exams were over, however, I hesitated too long about applying to a technical school, and by the time I had made up my mind, it was too late and I had to wait until the following year, 1968.

In the meantime, I needed a job and found one making boxes at an envelope factory. I sat at a machine and pressed a pedal to staple the sides of the boxes together. After having done that for a few hours, I was sometimes so sleepy from the monotonous work that I moved to another machine, which made yellow envelopes. There were four machines for the production of envelopes in various colors. The yellow envelopes were not more interesting than the others, or the boxes, but the change helped keep me awake.

At lunchtime, I usually sat next to another deaf woman, who later became my neighbor. An Italian guest worker (which is what we called migrants in those days) often sat with us. He didn't have anyone else to talk to and must have felt more comfortable sitting with us because we didn't speak to anyone either.

After our breaks, we went back to our machines. I worked with

a very nice woman who liked to talk, and, forgetting I was deaf, often yelled over to me above the noise of the machines. Although my work was certainly not exciting, I was grateful for the job.

When the year was over, I could finally start my classes at the technical school in Copenhagen, located next to the Danish Broadcasting Corporation's headquarters and concert hall, now The Royal Danish Academy of Music. I wanted to live closer to the school and was looking for a room to rent. I was lucky to find a small, comfortable room in an apartment owned by a nice elderly couple. I shared the bathroom and kitchen with them, and while I was welcome to keep my food in their refrigerator, I bought a small one of my own that I could keep in my room. Our living arrangement functioned really well, and then unfortunately the wife died. The widower, feeling that the apartment was too large and empty, asked if I had a deaf friend who might be interested in renting a room. I found a classmate who moved into the room next to mine, and once again the apartment felt more bustling and lived in.

My classmates at the technical school were mostly male. Kai and Peter, who were hard of hearing, had also gone to Nyborg School: I welcomed their familiar faces. Freddie, another young man who was hard of hearing, joined us later. He had been trained as a bricklayer, but after a work injury, decided to go back to school and become a technical assistant. Freddie was a real handful. One day a teacher strode into our classroom, and bellowing "This is not a saloon!," pointed to a tall cabinet with

an array of empty beer bottles on top. Freddie was indeed responsible for all the empties, because he and his friends used to drink beer after school hours.

We read many books on building codes during our studies. We also made technical drawings using architectural rulers, protractors, marker pens, and parchment paper. We often carried our drawings in long cardboard tubes so that we could work on them at home, along with any implements we might need. It would have been much easier for us to work on portable computers, but that luxury first came to Denmark in the 1990s.

We took a typing class and were not allowed to look down at our hands to "hunt and peck". We had to learn touch typing by memorizing the keys and typing with all our fingers on the keyboard, only looking at the paper we were typing on to see if we had made any mistakes. If we had, we corrected them with White Out and continued on. It may not sound like fun, but I actually enjoyed it and found it useful.

While written assignments didn't present any practical problems, there was always a sign language interpreter in the classroom during lessons, so that we four deaf students could follow along. We always sat together in the first row so that we had an unobstructed view of the interpreter, who stood next to the teacher. We also had an interpreter on hand for oral examinations, which would otherwise have been impossible.

When the day finally arrived for my final exam, I was really nervous. It was an oral exam and I was afraid I wouldn't be

able to explain myself well enough to the teacher and the external examiner through the sign language interpreter. The whole class was gathered in the hallway waiting to be called in to the green examination table one at a time. When it was my turn, I walked over to a desk covered with small strips of paper, each containing an examination question. I picked one and found to my relief that it was about how to plan a building site. I grabbed a piece of chalk and quickly began drawing on the blackboard, explaining as I went along, so that it was almost a lecture. My teacher and the examiner didn't interrupt me to ask any questions, nor did they ask for any further explanation afterward.

When my time was up, I went back out into the hallway to wait for my grade. Naturally, my classmates wanted to know how I thought I'd done, and they agreed that I'd been lucky in drawing such an easy topic. We were all on pins and needles. Finally the door opened and I was told that I'd been given an A. We stood there gaping, unable to believe that I'd done so well. So that's how I ended my two years at the technical school – good years indeed thanks to my classmates.

After my graduation in 1970, I moved back home with my mother while I looked for work. One day I saw an interesting job listing in the local newspaper. The Danish Geotechnical Institute was looking for a technical assistant. I contacted a deaf consultant, Mr. Hagedorn, who had also been my teacher at my school for the deaf, and asked him to get in touch with the Institute for me. Although he was able to arrange an interview, the Institute would

not guarantee that I could be considered for that particular job. As it turned out, they didn't offer me a job as a technical assistant, but one as a draftsman, as it was better suited to my handicap. Unfortunately, this meant a much lower salary, but I knew that with my deafness I would have to be prepared to accept such terms, despite my educational qualifications.

Some of our work at the Institute involved the soil analysis of building sites. For example, we collected soil samples from the bottom of the Great Belt as part of the preliminary studies for the Great Belt Fixed Link between the islands of Zealand and Funen. We mapped the structure of the seabed by drawing dots to symbolize sand and tiny circles to symbolize stone. The work took many months and filled many binders.

I was once interviewed for the Institute's newsletter, and the article about me ran under the headline: "Tap me on the arm." That came about because several of my colleagues didn't really know how to attract my attention while I sat at my drawing board. The interview gave me the chance to answer this question, and I hoped it would make people feel more comfortable around me. After all, some people feel awkward and insecure about how to relate to people with handicaps, particularly at a workplace. Fortunately, I felt that my colleagues were friendly and positive, and they found an easy way to let me know what they wanted me to do: They wrote me little notes.

I didn't have to toil at the drawing board all day. Occasionally large drawings had to be copied and mailed, and that was also my

job. I copied the drawings, folded them to fit the envelopes and sent them to the customers who had ordered soil samples.

Unfortunately, drawing was so hard on my eyes that after three years, I had to leave my much loved job at the Institute. It was especially hard to say goodbye to my colleagues, who had been so positive about working with a deaf person. I really shouldn't have chosen to train as a technical assistant, but as I have said, it was a popular choice, and I let myself be carried away by my peers.

I soon found a new job as a helper in a nursing home for elderly deaf people. There were no training requirements for the job at that time, so I was hired without difficulty, but in a "protected position," meaning that the municipality paid 40% of my salary and the nursing home the remaining 60%.

In terms of communication, the nursing home was a much better workplace for me than the Institute. It was wonderful to have deaf colleagues as well as hearing colleagues who knew some sign language, and to be able to communicate with the deaf residents. I really enjoyed being there, had very few sick days and was seldom late for work. However, my failing eyesight meant that I did have a few on-the-job accidents. One day when I was carrying a tray of medicine, I suddenly stumbled over a wheelchair that was being rolled into the hallway, and the pills scattered every which way.

A few days later, the head of the nursing home called me to her office. Coming right to the point, she explained that she was unable to fire me outright due to my protected position, but that she wanted me to quit my job immediately. I was stunned and asked

her how I could support myself without a job. She assured me that I would be granted an early-retirement pension due to my special circumstances.

By that time I had been working at the nursing home for nine years and really liked my job, so leaving it like that was extremely unpleasant.

This was the start of a long period of depression. I had always thought of myself as healthy and athletic, and certainly not as a pensioner: The two things were incompatible. So I struggled with depression for almost a year without advice or help from anyone. I felt ashamed of living the life of an early-retirement pensioner.

Finally, my family told me that I would have to stop feeling ashamed. They told me that while my handicap gave me no choice but to accept early retirement, it didn't have to define me as a person. Though I was relieved that my family was so understanding, I wished they'd given me that advice soon after I'd lost my job. Perhaps then I wouldn't have wasted a year struggling with my identity and might have found it easier to accept my situation.

So in 1983, at the age of thirty-six, I began my new life as an early-retirement pensioner. Adjusting to my new lifestyle wasn't easy, though I did my best to accept it. Every morning I got out of bed and speculated about what I would do now that I didn't have a job to go to. It took me a long time to accept this change in my life and finally overcome my sense of shame. Eventually I learned how to fill my life with new challenges that were no less meaningful than working for a living.

9. About RP and Usher Syndrome

Already while at the school for the deaf, I was sent for an eye examination at the nearby Institute for the Blind and Partially Sighted. Because of a minor astigmatism in one eye, I was given a new pair of glasses. After that I was summoned to eye examinations more frequently than my classmates, which did make me wonder. I learned later that I had begun developing an eye disease called Retinitis Pigmentosa (RP). RP is the result of Usher Syndrome, a genetic disorder resulting in reduced hearing or congenital deafness, impaired balance and RP. In brief, RP is a degeneration of the retina and I began developing tunnel vision. At the time, I was not aware that I had Usher Syndrome and RP, but the adults around me knew: my parents, my teachers, the ophthalmologist. I don't remember who told me about my disease or when, but I imagine that all of them wanted to shield me from the truth for as long as possible.

Later when I was about twenty-seven and knew about my diagnosis, I was sent for a thorough eye examination at the specialist eye clinic in Hellerup with a highly experienced ophthalmologist, Thomas Rosenberg. Meeting me at the clinic for the first time was Ejnar Madsen, a tall red-bearded man who was Denmark's first and (at that time) only consultant for deafblind people. He was there to interpret for me, and he smiled reassuringly.

The examination changed my life, because I was told that I had to prepare myself for the prospect of losing my sight completely. I burst into tears, and then tried to recover my composure by asking when it would happen. Dr. Rosenberg told me that he didn't know, and that it could be soon or not for a long time.

He advised me to learn Braille, just to be on the safe side. However, I have never had to use Braille, because I still have a few degrees of sight in my field of vision, just enough to be able to read and write using enlarged text – the so-called Zoom text – on computer.

I encountered Dr. Rosenberg again a few years later in 1986, when he was a guest speaker at the first nationwide RP conference that I attended. He gave an excellent lecture, factual and understandable, about Usher Syndrome. It was the first time I understood how RP actually works. I learned that RP covers a group of hereditary eye diseases that can appear in several different forms. Common to them all is that the photoreceptor cells (rods and cones) in the retina break down slowly. In time this reduces the field of vision, with some people developing tunnel vision, and others maintaining only their peripheral vision. People with RP may also develop light sensitivity, night blindness or blurred vision, and may also have poor balance. The disease can also cause total blindness. Those of us with tunnel vision have a field of vision of maximally 20-30 degrees, compared to 180 degrees in normal vision.

This information helped clarify some mysteries from my past:

why I kept tripping over guy lines at Scout camp, and why I was unable to bike to the beach with my classmates.

Time was allocated for questions after the lecture, and I had two: Was there anything I could do to maintain my residual sight as long as possible? Was there anything I could do in terms of diet? Dr. Rosenberg replied that he had made certain observations during his years of practice, though he couldn't back up his opinions with research.

First of all, he thought that having children was a disadvantage for women with RP. Lack of sleep and having to get up several times at night would be hard on the eyes. I had already thought that, given my handicap, it wouldn't be right for me to have children, but when I heard Dr. Rosenberg's reasoning, I knew that I had made the right decision. If I wanted to have any chance of maintaining my residual sight, children could not be part of my future.

That decision threatened to become a stumbling block for my immediate future, as I had already met the love of my life, Carsten, who is also deafblind. We became engaged during our Christmas vacation in Madeira in 1985, but we were not yet living together. The following year, we began planning our future. He lived across the country in Aarhus, and we agreed that I would move in with him, as he was almost completely deafblind at that point and would have had a harder time adjusting to a new place. We talked about the future and he told me that he wanted to have children. I felt obliged to tell him that I had already decided not to

have children, so that if he wanted them, he'd have to find another partner. Fortunately, he accepted me anyway and I moved to Aarhus in 1986. We have lived together ever since – just the two of us.

With respect to diet, Dr. Rosenberg advised avoiding dairy products, as there were indications that while they did not affect people with normal vision, dairy products worsened conditions for people with RP. I loved dairy products, so that bit of news was most unwelcome! However, I was definitely interested in preserving as much of my sight as possible, so I followed his advice.

In 1997 when I was fifty, I developed cataracts. Most people don't develop cataracts until they're in their seventies, but my eye disease brought the problem forward. My cataracts were removed at what is now Aarhus University Hospital.

Before the operation, I was asked if I wanted a local or a full anesthetic, and I chose the former. Else Marie Jensen, a consultant for deafblind people, held my hand throughout the operation, only releasing it at the end to signal that the operation was over. Afterward the doctor said that he wished more patients could be like me, and when I asked why, he replied that it was because I had remained so calm during the operation, despite its being performed under a local anesthetic. I assured him that I had wanted to convey my complete confidence in him by staying as calm as possible.

After a week with an eye patch, I returned to the hospital for a follow-up consultation. The doctor removed the eye patch and informed me that the results were as expected. I was certainly satisfied, and felt that I had been given a new lease on life. Although my field of vision was still limited, I could see clearly and even make out street signs, which I hadn't been able to read for a long time. The operation changed my life.

Even though I had been trying to follow Dr. Rosenberg's advice about diet and had cut way back on dairy products, I decided to eliminate cheese, milk and yoghurt altogether. From now on the only dairy product I would allow myself would be butter, which I simply couldn't do without at breakfast. I was determined to make a renewed effort to do everything I could to maintain the sight I had left.

In a further burst of determination, I contacted a private ophthalmologist in Aarhus. He charged 3000 Danish kroner for a blood test and a consultation, which was not cheap, but since he was from the U.S., I felt sure he would be up on the latest research.

The doctor informed me that I had type A blood and gave me a diet plan. Once again, dairy products were no-go. I protested weakly and asked if I couldn't be allowed a tiny amount of butter on my toast. The doctor grudgingly consented as long as I used organic butter.

To my regret, beef had been added to the list of forbidden foods. Did that really mean no hamburgers? I decided to follow the doctor's advice, and in fact I did feel better. I no longer experienced muscle pain, which had otherwise bothered me occasionally. I was impressed by this private doctor's skill.

Later I discovered why the doctor had wanted to establish my

blood type before recommending a diet. I saw an article in our local newspaper about a new book entitled *Eat Right 4 Your Type*. I bought the book for 300 kroner and soon realized that I had paid a private physician 3000 kroner to give me the same advice I could have read about in a book. Such is life. In any case, I was able to console myself with the knowledge that for many years, I had been able to maintain my good residual sight.

In time, however, my sight gradually deteriorated. By 2009 it was so poor that I should have begun using a white cane when I was outside, but vanity kept me from doing it. Two years later, I was forced to use a cane after breaking a leg (more about that later). Needless to say, while recovering from a broken leg, I was not as physically active as before, and I quickly felt the effects of less exercise. It has been shown that exercise is good for the eyes, and during the inactive period when my leg was broken, I could tell that my sight worsened. After that I didn't feel I had an alternative, so I forced myself to start using the cane. Once I was accustomed to it, I had to admit that it was in fact useful, and today I'm happy to have it.

In 2014 my sight took another turn for the worse when one of my retinas became detached. Retinal detachment affects about 600 older people every year in Denmark. Owing to my drastically reduced sight, I now have to depend on personal assistants (PAs), also known as contact people, as they provide contact with the rest of the world to people who are deafblind.

It was difficult for me to admit that I needed help from others,

and equally as difficult to ask for it. After all, I had been independent, autonomous and largely able to take care of myself until my mid-sixties. These days I'm unable to leave home without the help of a PA, but those are the conditions under which I live, and I am, of course, grateful for their assistance.

10. A rich theatrical life

The deaf theater world has played a large part in my life from my first entrance on stage in the 1960s until my final exit in 2000. It was a world open to me despite my loss of the royal senses, and it gave me many experiences that I would not otherwise have had. Together with my troop from the Theater for the Deaf in Copenhagen, I have appeared at the Liseberg Theater in Göteborg, Sweden, the ancient amphitheater in Athens, Greece and the Pantomime Theater in Copenhagen's Tivoli, among many other venues at home and abroad.

Not surprisingly, our productions were always pantomime. Pantomime is particularly well suited for deaf people – actors and audiences alike – because the story is conveyed by mime and body language exclusively: No one speaks. The essence of this form of theater is expressed simply but effectively in the two iconic masks representing comedy and tragedy.

We performed "Pierrot's Dream or Reality" in the Pantomime Theater in Tivoli in connection with the Danish Deaf Association's Golden Jubilee on May 17, 1985. There were twenty-three actors in the troop, and we rehearsed in a school gym under the direction of ballet dancer Morten Hansen. On the day of the performance, it was a thrill to be on Tivoli's famous stage before an

audience from all over the world. An added bonus for us was knowing that no one in the audience knew we were deaf!

I was reminded of the 1970s when my mother and I occasionally went to a Tivoli cafe for afternoon tea. We sat and signed eagerly back and forth, enjoying each other's company. On one of our visits, a waiter approached my mother and told her how much he regretted not knowing sign language. He spoke several languages including German, English and French, but not sign language. Although the incident was brief, his kindness made such an impression that I remember it vividly today.

Our troop performed at the Liseberg Theater in Göteborg on the occasion of the Swedish National Association of the Deaf's Golden Jubilee in 1972. The association held a theater festival with participants from the Nordic region. We were housed in a dormitory near Liseberg that wasn't occupied during the summer. Each theater troop had a single evening in which to entertain the others. When it was Denmark's turn, we decorated the stage with Danish paper flags, and performed a sketch involving a boxing match for women, in which I was one of the boxers.

The sketch called for the "referee" to stop the match at a certain point, because a boxer's bra had come unhooked, and that sent a roar of laughter through the crowd. After the performance, we were surprised when members of the audience came on stage, took down our paper Danish flags and waved them around. Now that's what I call an enthusiastic audience!

A few months later I received a copy of the Association's

newsletter, which included a review of our boxing sketch. It was written by Leif Sandberg, who had given sign language lessons to Sweden's Queen Silvia. He had seen our sketch and wrote that it had been ages since he'd seen an audience burst into the kind of laughter that makes your stomach muscles ache. That was quite a tribute.

The Theater of the Deaf in Copenhagen was not Denmark's only troop for deaf people. There were other groups in cities like Aarhus, Aalborg, Fredericia and Odense. In 1982, the Danish Deaf Association arranged Cultural Days for the Deaf in Fredericia, which included a theater competition for the troops from each of those cities. Another participant was a theater group for the deafblind – the Deafblind Theater Club – which had been established in Fredericia in 1981, the first of its kind in the world. The sponsoring organization, the Danish Deaf Association, was to select the best performance, and the winner would then have the honor of repeating its performance at the Nordic Cultural Days in Lillehammer, Norway, the following year.

Some people were no doubt surprised when the competition was won by the Deafblind Theater Club. After all, it was new, not to mention that didn't deaf people have an advantage over those who were deafblind and moreover more experienced? They won with an excellent comedy, *A Trip to Mallorca*, which they had written themselves. The deafblind community in Fredericia felt that their theater club had really done them proud.

The comedian Ove Bejsnap, co-founder of the Deafblind

Theater Club, later became chairman of the Danish Deafblind Association when it was established in 1987. It is interesting that a theater club for deafblind people existed for several years before an association was formed.

When I joined the Theater of the Deaf, I was among friends: Annegrethe Pedersen from my Nyborg School days and Erik Svendsen, who had been a teacher at my childhood's school for the deaf was now our stage director. Over the years, the Theater of the Deaf toured with many productions, including Holberg's *The Transformed Peasant,* Dario Fo's *The First Miracle of the Infant Jesus,* and *Cabaret*, which was filmed in cooperation with the Danish Deaf Film Company. Annegrethe and our instructor spent three weeks painstakingly translating Dario Fo's work into sign language, after which we had numerous rehearsals, as the language level of the play was so high. Annegrethe, Bodil Sørensen, Evan Kallerman and I had roles, and we gave performances at Jomfru Anes Theater in Aalborg, Theater Boat Liva in Copenhagen, and Helsingør Theater in Old Town in Aarhus.

While we were performing in Copenhagen, our instructor met two medical students who found it hard to believe that deaf actors could adequately perform a play of that caliber. Erik suggested they attend one of our performances, after which they had to admit they were surprised and impressed that deaf actors could perform as well as those who can hear.

Some members of the Theater of the Deaf also had the opportunity to travel abroad. In 1982, three of us attended a one-month

international summer-school course for deaf people at The National Theater of the Deaf in New London, Connecticut, about 240 miles northeast of New York City. My friend Annegrethe and I were asked to write a report for Mimi Jakobsen, Minister of Culture, about our experience. It was one way of thanking the Danish people for the financial support that had made the trip and the course possible.

Before we went, we studied hard to learn American Sign Language, as all instruction would be taught in ASL. Since I had learned to read English at Nyborg School, it was much easier for me to grasp this new sign language.

Most of the other participants were from the U.S., but there were also three from Japan, one from Malaysia, and one from Australia. Colin Allen, the Australian, is the current president of the World Federation of the Deaf (WFD). We got to know each other well, thanks to the rather daunting team-building exercises that were part of the program. One exercise was to throw ourselves off the stage, trusting that the eight people standing below would catch us in mid-air. I have to admit that I wouldn't be able to do that today, but back then it taught me the importance of trusting my fellow actors.

We were kept to a strict schedule, starting early in the morning with physical exercises and continuing with instruction until evening. We had only one day off, Saturday, and if we were free on a Friday evening, we all piled into three cars – seven to a car – and drove into town, where we went to nightclubs and reveled

in our freedom to dance and party until duty called again Sunday morning.

Toward the end of the course, the head of the theater school, David Hays, invited us to his summer cottage on the cliffs near New London. He prepared lobster that he had caught himself: what a treat!

When I returned home, I discovered to my surprise that I had lost eleven pounds during that one month – the opposite of what usually happens on trips to the U.S. It must have been that busy program of physical exercises and acting classes that kept me moving constantly.

A year later one of the participants, Charles, an American who was deaf and taught deaf people, came to Copenhagen. I showed him around Copenhagen on a tandem bicycle. Yes, I had finally bought a tandem, which I had missed when I was a student. He sat in the front, with me behind him. Whenever I wanted him to turn, I tapped him on the right or left shoulder, so he wouldn't have to turn his head. We biked down to the quay to see the Little Mermaid, and on to Amalienborg Palace, home of the Danish monarch, the Marble Church, Royal Theater, Parliament, City Hall and other sights. It was a lovely trip without incident, and I think Charles enjoyed his stay in the Danish capital.

During the summer course in New London, we had skimmed through a few of the shorter plays by William Shakespeare, the undisputed master dramatist of all times. Like most people, I was familiar with *Hamlet* and *Romeo and Juliet*, but I didn't re-

ally know much about Shakespeare himself, so when I was home again, I decided to learn more about the man.

I started off with a fine red-bound book my father had given me: "The Living World." One chapter entitled "Theater is a Living Art" by Palle Lauring dealt with Shakespeare. I learned that he had written long plays meant to be performed over an entire day. One of the pleasures people had in the 1600s was to pack a basket with food and go to an outdoor theater for the day. I also learned that while Shakespeare usually featured men in leading roles, many of his comedies had leading parts for women. However, men usually played the women's parts, as women were not yet accepted on the stage, which added to the comic effect. I found the information fascinating.

Several years later I went to Göteborg, Sweden with Bodil Sørensen to see Shakespeare's play *The Tempest*, performed by the professional deaf theater troop Tyst Teater. The Swedish actors were surprised to see us sitting in the audience, as they remembered us from our Golden Jubilee performance in Liseberg in 1972 and other occasions. Even though we hadn't seen each other in years, they hadn't forgotten us. Aside from the excellent performance, I was impressed by the number of hearing members of the audience who had come all the way from London. They could not have understood the dialogue in Swedish sign language, but were presumably so familiar with the play that they could follow the action anyway. What an acknowledgement of the theater's renown!

Another memorable trip I made with the Theater of the Deaf

was to Barcelona in about 1983. We went there to take part in a theater festival, but there was much dancing as well. One dance performance I remember in particular consisted of a group of deaf women in colorful Spanish costumes. Their movements were so beautifully coordinated that I thought some of them must have been "merely" hard of hearing and were setting the pace for the deaf dancers. In any case, I was fascinated and impressed.

Another surprise we encountered there was that deaf people in Spain are allowed to have a driver's license, but they do, however, have to put a special sticker on their cars as a warning to other drivers that they're not allowed to drive faster than fifty miles per hour, even on the freeway.

While we were at the beach I had an experience that made a big impression on me. We had stopped at a cafe, and while we were sipping our coffee and enjoying the Southern ambiance, I was suddenly approached by a woman holding a baby in her arms. Her clothes were ragged and she held the baby out to me as if she wanted me to take it. She stood there for a long time while I kept shaking my head until she finally gave up and left with her baby. I was upset and felt very sorry for the woman.

I had many wonderful experiences during my time with the Theater of the Deaf, and it's a shame it no longer exists. The theater was founded on September 5, 1960, and I helped celebrate its Silver Jubilee in 1985, before it closed its doors five years later due to a lack of funding, though we only found that out in 2013 when the treasurer died and the financial details came to light. It's sad

that the Theater of the Deaf, which brought such pleasure to so many people, should have closed for economic reasons. Fortunately, most of my memories are positive.

I was able to continue my interest in the theater at Castberggård, a learning and vacation center for people who are deaf or hard of hearing established in 1973. To provide more opportunities for deaf people in 1986, Castberggård added a cultural center and a folk high school (offering adult education with no prerequisites, no exams and no grades). Bodil Sørensen from my theater troop was hired to head and teach the drama department. I later took some of the courses offered there, and when the Danish Deafblind Association's theater committee was established in around 1990, I was appointed as a stage instructor.

My work with the deafblind theater group produced some wonderful performances of which I am very proud, particularly *The Danish Constitution* and *Louis Braille's Life*, because I played an active role in the creation of both of these plays.

In 1998 – the year before the 150-year Jubilee celebrating the birth of the Danish Constitution – the Danish Parliament contacted me about the possibility of offering support to any theater group willing to put on a performance about the constitution.

The idea was received with skepticism by our board, who thought the constitution was too dry a subject for a play. However, I was determined and wrote to Parliament myself, which shortly thereafter agreed to support the project.

In preparation for the play, I felt it would be a good idea to read

Rehearsal for the Deafblind Theater's performance of The Danish Constitution, 1998

Five participants in the Deafblind Theater's performance of The Danish Constitution in honor of the 150-year anniversary of the adoption of the constitution. Shown are three deafblind amature actors and two deafblind assistants: from left: Irma Busk, Torben Egense Hansen, Anne Malmbak, Ulla Kristensen and Eva Olesen. Kirsten Malmbak, who wrote the play, took this picture at the pre-premiere. The male actor may be showing a stack of documents to one of the women, while Anne is communicating with the woman on her left. All five participants are wearing identical white short-sleeve t-shirts printed with two longitudinal stripes of three Danish symbols for paragraph shifts in legal documents (§ § §).

Color photo, Castberggård, 1998. Photographer: Kirsten Malmbak.

the Danish Constitution, which I imagined to be a lengthy document. In fact, it's only four pages long, which made my work a lot easier. I asked my actors, Torben Hansen, Eva Olesen and Anne Malmbak, to select and study two or three sections of the Constitution's clauses, while I boned up on its history.

When we were ready to present the play to an audience, we held a dress rehearsal at Castberggård on June 5, 1998. The Minister for Culture, Elsebeth Gerner Nielsen, was in the audience. Many people were enthusiastic and told us afterward that the play had given them insight into a subject they knew little about. It was a pleasure for me to learn that we had added to the knowledge of many deaf and deafblind people, and I was pleased with myself for having stood by my conviction that we should put on the play. I informed the board with barely conceived delight that the play had been a success. The next year, I arranged a tour in connection with the Constitution's 150-year Jubilee, and we performed the play several places in Denmark.

The idea for a play about Louis Braille arose from a meeting at the Danish Library for the Blind, now the National Library for People with Reading difficulties. The library staff had heard about the Danish Deafblind Association's theater committee, and that gave them the idea of sponsoring a play for the library's Golden Jubilee. Since they were open to suggestions regarding the subject, I suggested a play about Louis Braille, the man who invented a special alphabet system that enabled blind people to read, and they were enchanted with the idea.

Even though I knew who Louis Braille was, I didn't know much about the man. So I bought a book about him and his life, which formed the starting point of the play.

I learned during my reading that Louis Braille had faced many challenges. Born in France in 1809, he was blinded in an accident when he was only three, and suffered from poor health throughout his life. Fortunately, he was a bright child and already as a school boy was frustrated by the poor tactile reading and writing system for blind people available at the time. By the age of fifteen, he was already developing the tactile system now known as "Braille." Unfortunately, his initiative was not acknowledged by educators, and he did not live to see his invention in use before his death in 1852.

When I read about the opposition to Braille's invention, it reminded me of the resistance to sign language in Denmark and other countries. Sign language is the language we deaf people find most natural to use and which gives us the clearest communication, but getting it acknowledged in Denmark and the rest of the world has been an uphill battle. Because deafness has regrettably long been associated with low intelligence, society has felt justified in thinking it knew what was best for deaf people without consulting them. At the infamous congress for teachers of deaf people in Milan in 1880, participants voted to ban sign language from the classroom so that deaf people would learn to use spoken language. For a very long time in Denmark, teachers also refused to use sign language, relying instead on MHS [hand signs supporting lip reading by showing not-visible consonants]. MHS was certainly used when I was in school, the thinking being that it would have a better chance of integrating deaf people into society, but perhaps also because it was easier for the teachers.

This was the background for the creation of the play *Louis Braille's Life*, which we performed at the library for their Golden Jubilee. It was such a success that a second performance was held in Køge in conjunction with an international conference for the employees of libraries for the blind.

I quit my work as a theater instructor in 2003, when I was elected vice chairman of the Danish Deafblind Association. This was such a demanding job that there was no longer room for the theater in my life. It felt right to put the theater behind me and set out on another worthwhile path for the association. I will always be grateful for the many precious relationships I forged in the theater world. Not only did it enrich my life, but it also convinced me and everyone around me that deafblind people can do so much more than expected.

11. Art instead of music

When I was a teenager in the mid-1960s, I once told my mother that I wished I'd been born hearing. She replied short and sweet that if I'd been able to hear, I would have wasted all my time listening to music! I remember being surprised at her answer, but she may have had a point. At any rate, the subject was not really up for discussion – music had been excluded from my life, and it was only natural that I developed an interest in the visual arts instead.

I understand that music has great significance for people who can hear, and that listening to good music can affect people emotionally and heal body and soul. I'm familiar with all the major music festivals in Denmark. For those of us who are deaf, it can be interesting to watch the musicians perform, but clearly the music itself doesn't mean anything to us. Our focus areas are without sound: the visual arts and performances.

Many people are unaware that there have been many deaf artists in the world. One historical example I would like to highlight is Wolfgang Heimbach, court painter to Danish King Frederik III. His masterpiece "Hailing the King before Copenhagen Castle" from 1666 is still on display at Rosenborg Castle. When I look at Heimbach's wonderful work, I feel proud knowing that he was

deaf like me. He was a cultivated man who mastered several languages, including Latin. His art supports my conviction that deafness is not an obstacle to one's ability on either the intellectual or artistic plane.

I own an inspiring book in Danish by Peter Niemelä entitled: *Døve kunstnere I Danmark gennem 400 år – Deaf artists in Denmark throughout 400 years*. Rather unfairly, Heimbach is not included, because he was born in Germany (in about 1615). Naturally, there are many other talented deaf Danish artists, such as Andreas Hermann Hunæus (born 1814), known for his painting "On Copenhagen's Ramparts", and ceramicist Sten Lykke Madsen, who created the fountain sculpture "St. George and the Dragon" in Holstebro. Several of Madsen's works have been exhibited as far away as the U.S. and Japan. Although he is now eighty, he is still an active ceramicist.

In about 1972, several of us got the idea of forming an art association for deaf people, which led to the founding of the Danish Association of Deaf Artists on March 30, 1972. Ernst Pedersen was elected president and I vice president. The president as well as the rest of the board were all men over the age of fifty, while I, the only woman, was only twenty-five. The association included some of the artists mentioned in the book on deaf artists, including Solveig Sonne Hornshøj, Thomas Gul Larsen, Hanne Orloff and Knud Møller (who also served on the original board).

The purpose of the association was to provide a place where deaf artists, amateur and professional, could share their interest

in art and have the opportunity to develop their skills by taking courses. An additional focus was to acquire pieces of art that would be distributed to members on the basis of a lottery.

At one point, the association acquired a sculpture by Sten Lykke Madsen, and when lots were drawn after an annual general meeting, I was the winner. I was delighted to become the owner of such a beautiful work of art.

At our first board meeting, we had quite a long discussion about how to record the minutes of the meetings. The older gentlemen on the board were in favor of keeping detailed minutes, as was the custom, but I disagreed. I found their idea old-fashioned and suggested that we simply ask the secretary to make a short summary of our meetings. The rest of the board were not easy to persuade, but when I proposed a trial period for my idea, they reluctantly agreed.

After the meeting, we waited for the secretary to send us a summary by mail, which was how all our correspondence was handled before computers. At our next board meeting everyone agreed that my suggestion had been a good one and that there would be no need to keep reams of notes from our meetings.

The first art course was held at Castberggård in about 1973, the same year the Danish Deaf Association bought the building. At that point Castberggård had not yet been remodeled and was officially still a parsonage. We were able to arrange an art course run by Tillner Andersen, a minister for deaf people, who planned the course together with a few artists. During the course we used

the adjoining building, which we called the "stables", for painting, and we slept on the second floor of the parsonage.

I loved painting in the "stables" together with other deaf people who shared my interest in art. Tillner Andersen served as an interpreter between the deaf course participants and the teachers, who were hearing.

That was the first of the countless art courses held at Castberggård over the next two decades. In 1990 we held a two-week art course that finished just as the newly built sports complex was inaugurated. Danish Crown Prince Frederik, the protector of the Danish Deaf Association, cut the ribbon at the opening ceremony, then threw himself into a tennis match against the current deaf Danish tennis champion. We all stood behind the hedge surrounding the new tennis court to follow the match – and get a good look at the Crown Prince, who is extremely good-looking!

We had held an exhibition of our art works before the new sports complex was inaugurated. Six of my paintings with motifs based on swimming, soccer and tennis were included in the show. When the course was over and I stopped by to take my paintings home, I met unexpected opposition from the head of the course and the teachers. They suggested that I donate them to Castberggård, pointing out that if I left my paintings, they could continue to delight and inspire other people. A couple of my paintings are still hanging there, including the one with a tennis motif at the entrance to the sports complex. I think it was insightful of the head

of the course and the teachers to ask me to donate my paintings, and I'm glad I did.

The association also arranged various other activities such as visits to art exhibitions, art museums and short trips abroad to study art.

A large international exhibition for deaf amateur artists was held in Szczecin, Poland in April 1986. Solveig Sonne Hornshøj and I went to see the many interesting works from all over the world. I had contributed some collages, which had been submitted months in advance. We were very impressed by the exhibition that the Polish association of deaf artists had arranged. Visitors also came from Russia and Germany, and by using international sign language, we were able to have some fruitful exchanges with deaf artists from other countries.

We stayed in Szczecin for three days, which gave us time to walk around the city with its many beautiful old buildings. I remember in particular an ornate church and the magnificent Ducal Castle, with roots going back to the 1300s. We were quite the shutterbugs, but the Russian visitors couldn't afford the luxury of cameras, and instead sketched furiously in the small notebooks, which they carried with them everywhere. Their drawings were as lifelike as photos. I felt embarrassed that they could draw so quickly and precisely, while we simply pointed and snapped. They were true artists! However, my photos did end up in an article I later wrote for the Danish Deaf Association's magazine about the exhibition and our experiences in Szczecin.

We returned home from Poland by ferry in a rough sea. Solveig and I, sitting alone in the restaurant, gave our dinner order to a surprised waiter, who couldn't understand how we could summon an appetite with the ferry rocking so violently. We could see the waves slapping at the window next to our table, while we relaxed and enjoyed our meal. It was strange to realize that we were all alone with our astonished waiter.

After dinner we walked to the lounge, where we were startled by the sight of ashtrays rolling off tables. Only then did I realize that the waves were bigger and the storm wilder than I had imagined. Solveig calmed me down by recounting a ferry trip from Bornholm in even heavier seas that had ended well.

We arrived safely in Copenhagen, where the weather was fine and calm. A few weeks later I ran into Solveig again, and she confessed that she had been less than truthful: Her worst experience on the high seas had not been her ferry trip from Bornholm, but rather our trip from Poland! I forgave her at once since she had provided reassurance at a time when I need it.

I have also been to London, Paris and Florence to study famous works of art. In April 1986, we also went to Crete – this time not to look at art, but to create it. I was only able to join the group for the second week of the two-week program, as I had been touring with my theatre troop the first week. The other participants had kindly spent the first week sightseeing, so that I wouldn't miss so many art classes.

We carted easels and canvases all over the island in order to

paint the wonderful sights we found everywhere. One day we stood on a cliff at the edge of the sea in order to paint a small island we could see in the distance. It was difficult to find even ground where our easels could stand firmly, but the weather was fantastic. It was so hot, in fact, that I painted in my bikini. At the end, when we compared paintings, it was fascinating to see the variations in our perceptions and interpretations of the same thing.

We were accompanied on the trip to the cliffs by the volunteer interpreter and tour guide Erna Hindsgavl. I noticed at one point that she seemed tired, so I asked her if she felt all right. She confessed that she was being awakened early every morning by a rooster on a nearby farm. I couldn't help thinking that this was one of the few occasions when being deaf was an advantage!

Our return home was followed by an exhibition of our paintings. Our stay on Crete and the subsequent art exhibition still rank as one of the best experiences I've ever had with the Danish Association of Deaf Artists.

Another very special event that sticks in my mind was the Blue Exhibition held at Castberggård in June 1991. It was a fascinating exhibition of about sixty paintings, all in shades of blue, by the very talented deaf American artist Harry Williams. Sadly, Williams had died only two months earlier at age forty-two, but his work was much admired and acknowledged. Perhaps best known were his violins without strings – a commentary on how he saw himself in a hearing world full of sound. Williams apparently drew inspiration from his neighbor, who was a violinist. A con-

stant theme in his work, which is full of symbolism, is the position – or rather lack of one – of deaf people in a hearing world. The exhibition was a beautiful and moving experience for many people.

I wrote an article about the exhibition for the Danish Deaf Association's magazine, but I was delighted when deaf artists received even more attention. A journalist from a local newspaper wrote an article entitled "The best art from the deaf world" about Harry Williams, as well as all the cultural activities under the auspices of Castberggård. The article spread the word locally about the deaf world and the importance of art for people who are deaf, which was certainly a step in the right direction.

In conclusion I want to mention Anne Louise Bang, an artist whose work I very much admire. I once saw an exhibition of her raw but beautiful sculptures of the hand positions of the sign language alphabet entitled "Sign – Puzzle or Solution." Although sign language was the source of her inspiration, interesting enough, Anne Louise Bang is not deaf. When I turned fifty, I asked for gifts of money and used some of it to buy two of Anne Louise's sculptures, the signs for "C" and "K", since they are Carsten's and my initials. The two sculptures have pride of place at home on a shelf where we admire them by touch.

12. Daddy's girl

From the beginning, I was clearly Daddy's girl. We have the same nose, feet and build. The idea of having similar feet might sound strange, but we both have almost square feet with four large toes and a tiny little toe. Unfortunately that means we both have to buy shoes one size bigger to accommodate our toes. I have even had to resort to buying shoes in the men's department, when I couldn't find women's shoes to fit. That was certainly not fun when I was young, though I did finally manage to find one shoe store that carried women's shoes in size 9 and 10.

For my confirmation in April 1963, when I was fifteen, I found a pair of women's shoes with a little heel that almost fit. I wasn't used to wearing high heels, so they weren't my first choice, and the pictures taken on that occasion show that the shoes were indeed too big for me. These days there's fortunately a much wider selection of women's shoes in large sizes.

I've been told that the squarish shape of our feet originated in ancient Greece. True or not, it's an appealing idea.

Except for my unfortunately shaped feet, my father has given me much for which I am grateful. For example, he was always finding books to feed my curiosity on many subjects. He had always wanted to be a teacher, but back in the 1930s when he was a

child, his family couldn't afford to keep him in school. His mother died young, leaving her husband alone with five sons to raise. One brother took over the farm, and my father became a policeman. So my father enjoyed being my private tutor later in his life. While working as a policeman, he was too busy to take courses in sign language, as my mother later did, so we communicated by writing to each other.

As part of his job with the Danish Security and Intelligence Service, my father worked occasionally for the military and the royal family. This came with certain privileges. For example, I was once taken to see Her Majesty Queen Margrethe II receive Her Majesty Queen Elizabeth II as her guest. My father and I stood close enough to follow the event in detail. I was particularly impressed by seeing the Royal Life Guards march before the two queens. I also noticed how tall Queen Margrethe was compared to her guest: She strode ahead on her long legs while tiny Queen Elizabeth followed at a slower pace. At first our queen was unaware of having left her guest behind, but when she noticed, she took a few steps back to even the tempo. She repeated the maneuver more than once, as Queen Elizabeth had trouble keeping up with her brisk pace. I found that amusing.

In the midst of the ceremony, one of the Royal Life Guards fainted. The other guards moved quickly to pull him behind their ranks, so that the two queens didn't see the incident, but my father and I were near enough to see it all. I've been fascinated by the Royal Life Guards ever since. I remember one winter's day

watching the guards march from their barracks to Amalienborg Palace for the changing of the guard. One tall guarder played the flute, and when he lifted his arms, I noticed that his sleeves were too short. He looked quite comical next to the other soldiers. I couldn't help smiling at the sight and wondering if he was a new man who hadn't yet had his uniform adjusted properly.

Whenever I see the Royal Life Guards I think of Wolfgang Heimbach's 1666 masterpiece "Hailing the King before Copenhagen Castle" and the proud tradition it represents. It was through my father and the wonderful experiences we shared that I developed my interest in the Royal Family. Another aspect of my great respect for royalty and history is that I longed for a large family when I was growing up and came to regard the Danish Royal Family as an extension of my own. It helped me feel that my own small family was not so isolated.

After my parents divorced and my father moved in with his new girlfriend, he was clearly unable to take part in my life to the same extent as before. My sister and I only saw him every other Sunday. Our mother would bring us to an agreed-upon meeting place – often an ice cream stand –where my father was waiting. Although he and my mother were certainly civil to each other, my father refused to set foot in the house they had shared. After the exchange, we went home with my father, often arriving at lunch time. We spent the afternoon together with my father and his new partner, after which he took us back to our meeting place. So we didn't spend much time in his company. On those Sundays when

we didn't visit my father, my sister and I went to our grandparents in Roskilde.

However, he was still our father and he wanted to be part of our upbringing and our lives. Of course, we occasionally had the kind of minor disagreements young people will always have with their parents. I remember he was very much against my wearing jeans in the 1960s. I must have been in the vanguard here in Denmark, and he couldn't quite get used to it. When I pointed out to him that I was over eighteen and entitled to decide what I wanted to wear, there wasn't much more he could say.

So despite my parents' early divorce, my father continued to be a presence and source of support in my life. For instance, he stepped up at the beginning of 1979, when I needed to move from the apartment I was sharing with my first boyfriend, John, whom I had met at Nordic Youth Camp on Iceland a few years earlier. I went to see my father, who had moved back to Copenhagen. I explained my urgent need for a place to live, and he contacted a good friend who rented out apartments. I was lucky enough to be offered one rather quickly and in the same building as my father, near my old school for the deaf. My apartment was on the fifth floor and my father's on the third, which suited me just fine, as he was then unable to monitor my comings and goings.

From my apartment, I had a wonderful view of the swath of green park by Krebs School, which Crown Prince Frederik and his brother Prince Joachim attended at the time. The two princes played in the park occasionally, and I sometimes saw them arrive

in a car with royal license plates. The chauffeur, dressed in a white cap and jacket, stood waiting for the boys while they played. One day the chauffeur, who must have been in a playful mood, invited me to sit in the royal car – though, of course, he didn't drive me anywhere.

I think it was a stroke of luck that I ended up living so close to my father. It gave us the opportunity to make up for some of the time lost after the divorce. By then my father was retired, and so he had plenty of time to help me by typing letters or finding information I needed. Since I was working full-time at the nursing home, I didn't have much time to spare. We were close in the last years of his life.

It was my father who helped me gather information at the end of 1979 when I was planning a trip to Egypt with my friend Kresten. We wanted to leave during the Christmas holiday and celebrate the New Year in Egypt. My father found all the information he felt would be useful, including the history of Egypt, and put it in a binder for me.

We kept a diary during the trip, which I gave to my father when we returned. He typed up our notes and put them in a booklet, one for Kresten and one for me, which I thought was a lovely gesture.

As time went by, I could see that my father was getting old and his health was deteriorating. He was a heavy smoker and had developed asthma, which made some of his daily activities difficult. I was able to help by cleaning and vacuuming, though I made it a condition that he had to air out the place before I arrived. I'm sen-

sitive to tobacco smoke and smells, which can make me quite ill. Fortunately, my father did as I asked, and as thanks for my help, he gave me some pocket money, as if I were still a little girl.

After my father suffered from asthma for a few years, his doctor told him he should quit smoking. Even a short walk made him struggle to catch his breath. When he turned seventy-five in 1985, his health was so poor he decided not to celebrate his birthday.

Shortly before Christmas that same year, my father's asthma was so bad he was hospitalized. He was allowed home during the holiday, but readmitted to hospital after New Year, where he stayed for the next seven months. Not long after he was readmitted, he was found to have bladder cancer. I lived a short walk from the hospital and was able to visit almost every afternoon. We wrote to each other as I sat by his bedside.

In April 1986, I very much wanted to travel to Crete to take part in the art course mentioned earlier, so I arranged for my father's good friend and neighbor to visit my father in my absence. Fortunately, nothing drastic happened, and I was happy that my father had not been alone while I was away.

When summer came, I took my partner Carsten to the hospital to meet my father for the first time. I was on pins and needles the whole time. My father was concerned because, like me, Carsten is without the royal senses. My father felt that it would be better for me to have a partner with normal sight and hearing. To that I simply quoted the title of a popular Danish evergreen: "It takes two." My father had no comment.

At the beginning of August, I suddenly got the idea to visit my father in the morning instead of in the afternoon as usual. I was feeling uneasy, and when I got to the hospital my father was fast asleep. I couldn't really talk to any of the staff, because I didn't have an interpreter with me, so without having talked to my father, I returned home, still worried, and decided to write a note to the friend who had visited him in hospital while I was on Crete. I later learned that my father died on August 6, 1986, while I was writing the note.

After my father's death, my mother cleared out his apartment. It was his wish that my mother, rather than any of the other women he had lived with, deal with his possessions. Despite their turbulent relationship, she was, after all, the mother of his two girls.

My father's urn was buried in the common grave in Holmen's Cemetery, across the street from the American Embassy.

As fate would have it, at this point I was already planning my move to Aarhus, and on August 15th – barely a week after my father's funeral – I moved into Carsten's two-room apartment. That was quite a bit of upheaval in a very short time, but I was grateful for the project of moving, which helped soften the blow of losing my father.

I sublet my Copenhagen apartment to a girlfriend, because I wasn't certain that my relationship with Carsten would last. However, I quickly felt at home with him and my new life in Aarhus. Our common interests were swimming and walking in the woods, and within only a few weeks, I knew that I wanted to spend the

rest of my life with him. So my grief at the death of my father was followed by a hopeful relationship that opened a new chapter of my life.

13. Amazing bicycle trips

While living in Copenhagen, I bought my first tandem bicycle, something I had wanted for a long time. Three times the cost of an ordinary bicycle, the tandem quickly proved to be worth every penny. When my American friend Charles visited me in 1983, the tandem took us through the streets of Copenhagen, and it also brought me on countless trips all over Denmark and parts of Sweden. I have wonderful memories from all these trips. I should mention that, for obvious reasons, tandem biking is popular in deafblind circles. Not only can we enjoy the freedom of biking through the landscape, we're also getting exercise.

I participated in the Lolland Round bicycle race in 1985 with my biking buddy and "pilot" Morten. We took the train to the island of Lolland, and I had my own faithful tandem bike with me on board. Our baggage was loaded onto a truck after our arrival and driven to the first destination. Sport centers along the route were designated as places where we could get a meal and a good night's sleep after each day's ride. The one we slept in the first night was divided into two sections – one for women and one for men – by a giant carpet suspended in the middle of the room. Bathrooms were in short supply, so there were always long lines. Our accommodations were far from luxurious, but we were so

exhausted after our first day on the road that we fell into a deep sleep and hardly noticed our surroundings.

The race was open to all bikers, not just tandems, so Morten and I had an advantage. We were a good team and able to pass the solo bikers, who teasingly accused us of cheating by being two to a bike. It was a great tour for all of us, in fact. We biked three 60-mile stages in just three days. Today I can't imagine having biked so far, but I do remember being saddle-sore.

Morten and I also participated in the Gotland Round race in Sweden, which had been arranged by the Association of the Swedish Deafblind. We took the train to Stockholm and then the ferry to Gotland, where we rented a tandem. As Morten and I are both tall, our rental bike wasn't a very good fit, but we managed to complete the race despite being too low to the ground for comfort.

It was exciting to see all the Swedish deafblind bikers, especially since I'd been the only one in the Lolland race. Luckily, I was able to understand Swedish sign language, so we had some good exchanges with other participants and generated a good community spirit along the way.

Each of my bike trips has given me good experiences and wonderful memories, but the one I took in 1984 changed the entire course of my life. It was a trip in Southern Jutland for deafblind people only. One day I noticed a handsome man wearing a GI jungle hat, and just to make conversation asked him if he were a "pilot". "No, in the back," was his curt reply.

Tandem trip 1988 at Castberggård

From left: Torben Egense and his pilot Sten Fisher; Kirsten Malmbak and her pilot Anne Dorthe; Carsten Thorup and his pilot Birgitte Worsøe. They are in front of the main building at Castberggård, a former parsonage converted into a learning and vacation center for deaf people. The two-story building is adobe in color, also the tile roof, with white trim and white window frames. Participants are three deaf-blind tandem bikers standing next to their bikes ready for their tandem trip along with their pilots, who are sighted and kneeling. The pilots will sit at the front of the bikes and steer underway. All participants are dressed for summer in short-sleeve shirts and shorts. Strapped to the bikes are small bags suitable for day trips. Photographer: Bodil Sørensen.

Well, okay, I thought: He's not much of a conversationalist, but he certainly has beautiful blue eyes.

The man in the hat turned out to be Carsten Thorup, the man I live with today. Although our first meeting back in 1984 fizzled out, fortunately we met again the following year on a course at Castberggård for people who had just been granted early-retirement status. I knew that he had problems with his sight and therefore would not be able to follow information on the large screen during the course, so I sat next to him and interpreted. As the days went by, I became more and more enchanted. My feelings were apparently reciprocated, and the rest, as they say, is history.

Two years later, Carsten and I went to the Faroe Islands where Carsten was taking part in a chess tournament. Chess has always been his great passion, and he was the only deafblind player in the tournament. It was held in the Nordic House in Thorshavn, an unusual building with a sod roof. As soon as the tournament was over, we flew back to Copenhagen, took the train to Køge where we caught the ferry to Bornholm and joined a group of deafblind bikers and volunteer "pilots" for a tandem tour.

Due to the hilly terrain and strong winds, biking on Bornholm was harder than on Lolland and Gotland. Still, we had some interesting sensory experiences underway. One was seeing and feeling The Seven-Masted Ship, which is not a ship at all, but an old tree that was toppled during a storm. Incredibly, seven of the tree's branches continued to grow upward towards the light until they

eventually looked like masts on a ship. Unfortunately, a storm has since wrecked the branches, and the tree is no more.

At that time, my residual sight was still quite good, but for Carsten, whose sight has always been poorer than mine, sensory experiences like this mean a lot. As my own sight has gradually diminished, I have increasingly learned to experience the world by feeling, smelling and tasting.

Another experience on the Bornholm trip that still stands out in my mind was tasting newly smoked herring, a real treat. It wasn't just the biking that was important to us, but very much the little experiences along the way. We got so much out of the opportunities to explore using our other senses. Those of us who are deafblind were particularly grateful to the volunteer "pilots" who made the trip possible for us.

Our trips to the islands of Ærø and Samsø were arranged by Castberggård, which for a number of years offered two-week tandem holidays every summer. Interest in the trips gradually waned, and tandem holidays were shortened to one week. Today young deafblind people do not have the same interest in tandem biking, which is a shame, because biking offers many experiences. Perhaps they want more comfort, and I have to admit that I do too. When I think about the trips in which we stayed overnight in sports centers or hostels, I'm amazed that I managed. Today I would insist on a hotel! But I'm glad that I set challenges for myself when I was young and had the energy, and I think all of us owe it to ourselves to do the same – whether it's a tandem bike

trip or something completely different, and whether or not they're deafblind.

In 2012 our tandem tradition flowered again when Henrik Ottesen from the Danish Deafblind Association got the brilliant idea of arranging a tandem marathon as part of the association's Silver Jubilee celebrations. Not only would it raise money for the deafblind cause, it would also strengthen the sense of community and offer a great experience. The race took off from Amager Beach Park, with members of the association, their friends and families participating. It turned out to be an extremely successful event. Having broken my leg the year before, I still had problems that kept me from biking, so was unable to ride a tandem. Instead, I rode in a sofa bike next to the pilot, which was much more comfortable than a tandem, but not nearly as fast. This time it was my turn to watch the other participants overtake us, and I couldn't help smiling at how the roles had reversed since my bike tour on Lolland twenty-seven years earlier, when Morten and I had left the others in our dust. That brought back memories, and while I sat reminiscing about the good old days, I couldn't help feeling that I had come full circle.

Acrylic painting of deaf-blind bikers on a tandem trip with their pilots, by Kirsten Malmbak (100 x 80 cm) from a painting course at Castberggård, 1990

The painting is naive in style, simple with clear colors. At left is blond-haired Carsten with Merete his pilot, both dressed in light blue t-shirts and navy blue shorts, and dark-haired Kirsten with her pilot Morten, both in red t-shirts. They are racing past two bikers on ordinary bikes and keeping up with each other on a gravel path. The one-man bikers are hunched over their bikes, pedaling hard, while the tandem bikers are upright and relaxed. The artist is showing us that it is easier to be two on a bike than one, which is part of Kirsten's life experience: It takes two. The artist's palette is light summer colors with a fertile green landscape featuring a small lake and blue sea as background under a cloudy sky: Denmark in the summer. Malmbak.

Carsten sailing in Kolding Fjord with his service provider, Ulla Kristensen, in the 1990s. Tour organizer: Castberggård

Carsten with a full beard is seated alongside his service provider, Ulla Kristensen, in the open deck between the masts of a two-masted wooden schooner. It is a gray day with only a light wind, the sails are not set and the boat is motor-powered. The coastline and a factory with a chimney can be seen in the background. Carsten and the other passenger are wearing warm summer clothes with slacks. Carsten is wearing a blue wool pullover sweater and his service provider is wearing a floral jacket. They seem to be enjoying the fresh breeze through their hair from the speed of the boat.

Color photo. Kolding Fjord in the 1990s. Photograph: Kirsten Malmbak.

14. Courses at Castberggård

Castberggård was established in 1973 as a learning and vacation center for people who are deaf or hard of hearing. The center has been important to many deafblind people over the years, because we feel that our lives have been enriched by is the courses offered there. I took my very first art course at Castberggård in 1973, and it's where I met Carsten for the second time when we took the same course for early-retirement pensioners in 1985.

In 1986, the same year I moved in with Carsten, Castberggård became a folk high school offering adult education with no prerequisites, no exams and no grades. I decided right away that I wanted to sign up. Moving to Aarhus from Copenhagen, where I had lived all my life, had been a major upheaval for me. After all, I was thirty-nine, a relatively late age to be packing up my belongings and establishing a new home base. I felt that the familiarity of Castberggård would make the transition easier. I asked Carsten if he wanted to sign up for the first school year as well, but he decided not to. Although I would have liked to have had him with me, I ended up going on my own, which turned out to be a good thing. Being together with other people who were deaf and hard of hearing from all over the country not only provided me with

a fixed routine, but also opened up my world and helped me feel less limited after the move to Aarhus.

Establishing a folk high school at Castberggård was the brainchild of Johannes Petersen, who was inspired by Norwegian and Swedish models of folk high schools for deaf people. Originally a parsonage, Castberggård has been owned by the Danish Deaf Association since 1973. However, in order to establish a folk high school on the site, more rooms, a library and a sports complex with a stage were needed. It took many years to acquire the funding to carry out these building projects.

The folk high school finally opened in 1986 and offered several programs, including the theater, which I enrolled in. The theater program was run by Bodil Sørensen, whom I knew well from my time with the Theater of the Deaf. Like me, she had also moved from Zealand to Jutland that same year, and in her new function as a teacher, she was also able to maintain her connection with her Zealand roots through Castberggård. She had many wonderful ideas and arranged the Nordic Drama Course for deaf people, as well as Castberggård's annual summer course for deafblind people (including tandem bicycle trips). She also arranged for a Russian deaf theater troop to visit Denmark.

The folk high school had another teacher named Bodil – Bodil Brixen – whom I also knew from Nyborg School. She was the head of the Danish program and taught a writing workshop that I attended all four times it was offered. It increased my understanding of the writing process, including how to formulate a text on

the basis of a specific idea. The course was highly instructional and still helps me.

During the year I was studying, I went home three weekends a month. Attendance was mandatory at the school that fourth weekend. When I was home, I shared my experiences at Castberggård with Carsten. He must have found it inspiring, because he agreed to give folk high school a chance, although he had to wait until fall, when the next school year started. Fortunately, we were able to spend the summer together before we "changed places": This time he was the one who left to study while I stayed home in our little two-room apartment. Since our apartment was rather cramped, being on my own at least gave me a little more space.

Carsten's change of mind came about not only through my accounts of folk high school life, but also through his interest in a course for people who had recently become deafblind, arranged by Castberggård's course leader, Niels Nielsen. The course was held in Fredericia in January 1987, which coincided with my return to school after Christmas vacation. Carsten and I traveled together by train, along with other deaf and deafblind people returning to folk high school. Carsten was supposed to continue on to Fredericia while the rest of us needed to change trains in Vejle. Unfortunately, that particular January was plagued by heavy snowstorms, making transport difficult. While we were underway, the conductor informed our group that we couldn't travel as far as Vejle, but would have to get off the train in Horsens. We clasped hands in dismay, but had no choice but to get off in Horsens, where we were

met by the school principal, Helge Simmelsgård. He explained that we couldn't continue on to Vejle, because so many roads were closed there due to the weather. Instead, he had arranged for taxis to take us to his home in Horsens, where we would spend the night. Carsten was the only one of the group to stay on the train, which was continuing on to Fredericia, though he planned to join us at Castberggård as soon as his course was finished.

When we arrived at the principal's home, we realized how busy he must have been making sleeping arrangements for all fifteen of us. Of course, there weren't enough beds for everyone, but neighbors had kindly lent us sleeping bags. The girls spent the night in the basement, and the boys in the attic. Two of the boys were coming down with something, so they shared a small basement room, to avoid spreading their germs to the rest of us.

Breakfast was served the next morning, but we had to eat in two shifts, as the kitchen was not big enough to hold all of us at once. The plan was for us to be driven to Castberggård in a van. It could only hold ten passengers, so Mr. Simmelsgård stayed behind, and the rest of us squeezed together.

We headed off on snow-covered roads, passing through a village where the snowdrifts were as high as the front doors. There were no people on the street and it was like driving through a ghost town. We made a brief stop at a small shop to buy groceries, which had been ordered in advance and packed in large boxes. Finding room for he boxes wasn't easy. We continued on our way, but were stopped by a massive snowdrift before reaching the approach to Castberggård. The driver was able to maneuver the van to the back of the building, where the snow was also high, but at least we could walk from there. We piled out of the van, fighting our way through waist-high snow, and finally made it to safety.

We were met by Johannes Petersen's sister Ruth, the custodian, who lived in a yellow house across from the entrance to Castberggård. She told us they'd once had an even worse snowstorm, in which the drifts came up to the top of the building, so that you could actually walk on the roof.

None of the personnel had been able to make their way through the snow, so only our group and Ruth were present. We had no choice but to take over the kitchen and start making dinner. Luckily for us, we had a baker on our team.

After breakfast the next morning, we learned that Helge Simmelsgård was on his way. Our job was to clear the road that led to the entrance. We battled the snowdrifts with every available tool and were filled with pride when he was able to drive his car all the way to the front door. We had even built a snowman outside the dining hall and taken pictures, which were later printed in the Danish Deaf Association's magazine along with a little story about our day in the snow.

The kitchen staff was still snowed in, but by now we were enjoying doing our own cooking. While we ate, we could keep an eye on our snowman, standing tall and proud outside the dining room windows.

Carsten finally arrived a few days later, along with course lead-

er Niels Nielsen. He and Carsten had shared a room in Fredericia, and Niels had lent him a book about Helen Keller. Carsten had enough residual sight at that point to be able to read, and he found the book inspiring.

Helen Keller is revered in the deafblind world. She was born in Alabama in 1880, and became deafblind at the age of nineteen months after a serious illness. Thank to Ann Sullivan, her private tutor, she learned to communicate and was subsequently able to attend school. She was the first deafblind person to earn a Bachelor of Arts Degree, and was later known as author, political activist and lecturer. She has been a role model and inspiration for deafblind people all over the world.

This was the start of many courses that Carsten and I took together. We once took a Personal Psychology course taught by Ulla Blanck. We were the only two deafblind people in the class – the other participants were deaf. We started off by being asked to make a drawing of whatever we wanted, after which our drawings would be briefly analyzed. Carsten drew a ship, an airplane and a car, while my effort was more abstract and "artistic." Carsten was told that he was adventuresome and loved numbers, which was certainly true – he's always adding up columns of numbers to make sure they're correct, not to mention that his adventurous spirit has often been put to the test on our many trips around the world. My drawing indicated that I'm a mess head, probably due to my love of art! We found it amusing to learn about ourselves and each other that way.

Folk high school has also provided us with new friends, including a man named Per Schmidt, also known as Per Clown, since he often performs as a clown. The job center was not enthusiastic about his choice of work, and it wasn't easy for him to get permission to train as a clown, but he finally achieved his goal, and I am delighted for him. When he performs wearing his big white gloves, I can easily follow his sign language and gestures before a crowd of children. He is indeed a capable clown.

Carsten and I have attended most of the summer courses for deafblind people arranged by Castberggård since 1988. We have enjoyed many canoe trips, paddling our way on various rivers and lakes. One time I was in the same canoe as our course leader, Stig Krarup, so while I had a competent partner, another couple ran into trouble. They kept paddling in circles, so Stig got the idea of tying their canoe to ours so that we could tow them behind us. It was such hard work, however, that I switched to another canoe when we stopped to rest. Stig had to continue towing his extra burden, but, after all, it had been his idea!

Another time, Carsten and I teamed up with Bodil Sørensen. Carsten sat in front, with me in the middle and Bodil in the back to steer. When they veered off course, Bodil would slap the side of the canoe to send a vibration to Carsten so that he would stop paddling and let her take over until they were back on course. This signal was repeated so many times that hearing canoers must have wondered what all the noise was about.

We used to go canoeing without any supervision, but regula-

tions were tightened after a serious accident in 2011, so that nowadays deafblind people who canoe have to be accompanied by an instructor.

Castberggård also holds courses for families. The summer courses for families with children are particularly popular, as they appeal to the large group of deaf parents with hearing children. Since the majority of deaf parents have hearing children, communication and play are definitely a challenge. The summer courses focus on these areas, and there's often a waiting list.

There are also courses for hearing parents with deaf children. Carsten and I were surprised to learn one summer that our mothers had gotten together and signed up for a sign-language class. As coincidence would have it, they are both named Grethe, and have many other things in common. They even shared a room while at Castberggård.

During the course, they took part in a stage performance of Hans Christian Andersen's *The Tinder-box*. Much to our amusement my mother had the role of the witch, while my mother-in-law was the princess. It meant a lot to us that our mothers had forged a strong friendship, and had made the effort to strengthen their relationship to us, their children, although we had long been adults. Taking a course may not sound like a life-changing event, but my story hopefully shows that some courses have been pivotal to my relationships with others, first and foremost, to my beloved Carsten.

15. Ignorance

What do I mean by ignorance? I could have chosen the word "prejudice," which springs from ignorance. However, I have decided to stick with ignorance, which is less negative, in the hope of showing the kind of tolerance I have sometimes longed for in return. The ignorance I am referring to here is what I, as a deafblind person, have encountered in my interactions with people who can see and hear. One example already mentioned in Chapter 10 is the encounter between our theater troop and the two medical students. Before they'd seen us perform, the student didn't believe we could put on a production at the same level as hearing actors. They expressed an assumption about deafblind people rooted in ignorance about our abilities, and one I have met many times. In the following, I will provide more examples that illustrate the topic from various perspectives.

I'd like to start by highlighting a recent example of what deaf people can achieve. In 2016 the young American model and actor Nyle DiMarco accomplished something no other deaf person ever had and which no one believed possible: He won the "Dancing with the Stars" contest. That elicited reactions from all over the world and sparked an incredible sense of pride in the international deaf community. Nyle learned the dances by memorizing the

choreography and following his partner's moves. He even performed some of the tango blindfolded, thus dancing as a deafblind person.

If you find it hard to imagine how anyone can enjoy dancing without hearing the music, I suggest you check out Nyle's performances on YouTube. You will see that he dances with his emotions and finds delight in moving his body. Deaf people can also feel musical vibrations from the floor. Nyle has achieved a victory and opened the door to a world that was previously closed to deaf people. A ripple effect could already be felt a year later in 2017, when a deaf woman became a contestant on the Polish version of "Dancing with the Stars."

To cite some examples of ignorance about deafblind people from my own experience, I need to go back to the 1980s when – despite my own vision problems – I served as a personal assistant (PA) to deafblind people. To begin with I had only positive feedback about my work. My first assignment was to accompany my twin-sister on a group tour for deafblind people to Garda Lake in Italy. She could have asked for a different PA, but she felt comfortable with me. The trip was arranged by the then head of the deaf and deafblind nursing home in Nærum together with Asger Andersen, Lutheran minister for the deaf, and it must be said that both men did an excellent job planning the trip and our accommodations.

Asger Andersen also traveled with us to keep an eye on things. One evening when I was relaxing in the hotel pool, I caught a

whiff of cigar smoke and knew at once that Mr. Andersen was nearby looking after me. That wasn't really necessary, as Anne and I were managing fine. Well, except for one minor incident when we were playing with a beach ball in the pool. The ball landed next to Anne, who grabbed it – or at least she thought she did – and then realized she was holding the head of a bald man! But that's the kind of thing that happens to deafblind people, and even though it can be embarrassing, we have learned to laugh it off.

A more serious incident occurred a few days later. An older man serving as a PA fell down some stairs and broke his arm. Since the deafblind man he'd been accompanying could neither hear nor see what had happened, he froze halfway down the stairs. The injured man was taken to the hospital, but he had to resume his function the next day, as the deafblind man had no one else to help him. The rest of the trip went well for Anne and me, and although I was tired when we returned home, I felt confirmed in my ability to serve as a PA.

My next assignment came about through my job at the time in the nursing home for elderly deaf and deafblind people. I accompanied one of the residents, a sweet deafblind woman named Marie, on her vacation to Spain. She had never traveled beyond Denmark's borders and got her first passport as a senior citizen! Luckily Marie was open to new ideas and not afraid of foreign customs. She was unfailingly positive, praising the hotel, the weather and our little trips.

The only thing that bothered her was that we'd been instructed

to drink bottled water rather than tap water. Although I was used to this precaution and had never considered it a problem, I could understand why Marie found it so strange. It was a pleasure for me to share her first experience abroad, and I was pleased that the trip was a success for both of us.

On my third trip as a PA, I accompanied my own partner Carsten on a group tour for deafblind travelers to Tunis in 1985. Unfortunately, the other PAs – all of them seeing and hearing – considered me unfit to be Carsten's PA, since I had a handicap of my own. I felt hurt, particularly after the positive experiences from my first two assignments. I considered myself every bit as qualified as they were and decided to go out of my way to prove them wrong.

The trip went well, and I felt I had done my best. The evening before our return home, our tour leader Ejnar Madsen (the consultant for deafblind people who had interpreted for me earlier) praised me for a job well done. His acknowledgement meant a lot to me, particularly because it had been made in the presence of the other PAs, who fell silent. I could not have asked for greater confirmation of my abilities.

What might come as a surprise is that deafblind people are met not only by skepticism from people who are seeing and hearing, but also from among our own ranks. In fact an equal amount of skepticism comes from people with handicaps. The founding of the Danish Deafblind Association is a case in point.

Before then, deafblind people had to decide whether they be-

longed to either the Danish Deaf Association or to the Danish Association of the Blind. The initiative to found an organization for deafblind people was taken by Ove Bejsnap and Carsten Husted.

Ove is the child of two deafblind parents, and his father's dying wish was for deafblind people to have their own association. Ove made it his mission to realize his father's dream, and he joined forces with Carsten Husted. The two men quickly discovered that it was easier said than done. When they presented their idea to the two existing organizations, they met unexpected resistance. Neither group believed that deafblind people would be able to run their own organization, and they refused to support the initiative either politically or financially. Ove and Carsten then turned to Ejnar Madsen, consultant for deafblind people, and Svend Åge Sundgård, then the head of the nursing home for elderly deaf and deafblind people in Nærum. Fortunately, both men were positive about the idea and gave it their full support. With their help and encouragement, Ove and Carsten forged ahead toward their goal, and the Danish Deafblind Association was founded in 1987. Twenty-eight people joined the association that first year, and Ove Bejsnap was elected chairman. The Danish Deaf Association and Danish Association of the Blind were surprised to learn of its founding but finally offered their financial support.

At the Danish Deafblind Association's ten-year jubilee, the two older organizations acknowledged that the new association had been a success. So much so, in fact, that it was strong enough to

manage on its own financially, and the two once-skeptical organizations were able to end their financial support.

Another widespread problem is the skepticism deaf people meet on the job market. According to statistics, only 38% of the deaf Danish population was employed in 2016, compared to about 70% of hearing people. Here I must emphasize that the disparity is not due to the lack of skill or will on the part of deaf people, but rather to the skepticism of employers and their employees. A 2015 survey from the Danish Council of Appeal on Health and Safety at Work shows that 60% of the hearing population does not believe that a deaf person is able to work, and only 38% of the employed hearing population would unhesitatingly agree to work with a deaf colleague who had the necessary qualifications. Statistics like that suggest that people need to change their attitudes about those who are deaf or have other kinds of handicaps. While I'm sorry to note that the outdated perception of deaf people as being somehow less intelligent is still alive and well, I also suspect that the prospect of working with a person who is deaf is somehow frightening to people who can hear. To some extent that's understandable. After all, very few people have any experience being around people who are deaf, and do not know how to act around them or communicate with them. The general public needs to be educated and informed. Prejudice and anxiety will not be eradicated until this social barrier is breached and the hearing segment of the population learns that people who are deaf or deafblind can be fully competent employees despite their handicap, and that

they have as much to offer as anyone else with the same qualifications.

It's possible that other countries are more successful in breaking down these prejudices than Denmark. A deaf acquaintance who was unable to find work in Denmark applied for and got a job in Lithuania. The last I heard from him, he had the same job, and was very satisfied.

My personal assistant, Günay, who is Turkish, tells me that in Turkey deaf people have been more fully integrated into the workplace and that it is far more usual to meet them at work than here in Denmark.

My examples so far have dealt mainly with the lack of trust in the abilities and qualifications of deaf and deafblind people, but I'd now like to touch on a subject that illustrates another aspect of this lack of trust: Cochlear Implant (CI). CI is a hot-button topic in the deaf community, and many deaf people feel that their opinions are not being taken seriously. Deaf people see many difficult aspects of this technological advance, and dealing with children with CI is a particularly sensitive issue. After all no one can follow a child's development or have a better understanding of a child's needs than parents. However, many deaf parents of children with CI find that medical opinion about their children's needs is in direct conflict with their own experience. Doctors often try to persuade the parents of children with CI to abandon any form of sign language, believing that the children will then learn spoken language more quickly. What that means, however, is that for a

period, a child with CI in a deaf family is robbed of the only form of communication he or she knows, which deaf people perceive as child neglect. Deaf parents believe that sign language supports language development, and makes the transition between the two forms of language easier without delaying development. Their position is supported by experience from other countries, including the U.S.

This debate brings back memories from a time when sign language was banned in schools and children were pressured to use spoken language. Then, too, the opinions of deaf people about their own needs were disregarded. This same type of frustration is now being felt by deaf people in the CI debate. Once again there is a lack of respect and understanding, with hearing people claiming to know what is best for deaf people, rather than paying attention to what deaf people want.

I hope I've been able to provide some insight into the challenges and problems faced by deaf and deafblind people every day, from skepticism about their abilities to general ignorance and prejudice. I hope this greater insight will result in more understanding and respect. Although Denmark's official approval of the use of sign language has been a step forward in the recognition of the abilities, needs and rights of deaf and deafblind people, it is a long process that will require much more effort if we are to reach our goal.

Carsten and I at my 40th birthday party, one year after we started living together in Århus. Party dress code: red and white

Kirsten and Carsten are locked in a tight embrace, holding hands behind each other's backs. They are smiling in delight, standing in front of an open door at the Deafblind Association building in Aarhus, where the party was held. Kirsten is wearing glasses. Her full-length dress has diagonal stripes in red and white. Her hair, darker than Carsten's, is medium length and styled with a pony tail to one side. He is about 4 inches taller than Kirsten, and his blond hair is short and parted on the right. His beard is trimmed and he is wearing a short-sleeve Hummel soccer jersey and matching shorts featuring red and white stripes and the red Hummel chevrons.

Amateur color photo. Aarhus Deafblind Association building, 1987.

16. Carsten "Chess"

As the observant reader will have noticed by now, sign- language users typically give the people they know a name sign that represents a certain trait or characteristic of that person. My partner Carsten's name sign is "Chess," which certainly says a lot about his favorite hobby.

Chess has been his passion since childhood. As my knowledge of chess is limited to the names of the pieces, this isn't an interest we share. When Carsten and I first met, we realized that our common ground was sports and exercise, and after we started living together in 1986, we enjoyed swimming and taking walks.

Carsten was born into an athletic family. His mother, Grethe, played handball, and his father, Orla, was a goalie on a soccer team. While Carsten's sight was good enough, he played both handball and soccer.

Grethe was born near Aarhus in 1926 and moved to Grenaa as an adult, where she first worked in an office and later for many years in the town's steam-powered weaving mill. She and her co-workers wrote a book about their working lives.

Orla was born in Randers and owned the only hairdressing salon in town. He was a well-known figure and often mentioned in the newspaper in connection with the local soccer club.

Grethe considered Orla quite a catch, and she called him her "goalie." They were married in 1953 and lived in Grenaa.

Carsten was born two years later. He was born at home, which was quite common in the 1950s, especially in the provinces. Once when we were visiting Grenaa, he showed me the large yellow house where he'd been born and raised.

Grethe stopped working for two years after Carsten's birth, but in 1957, when she took a new job as a part-time bookkeeper, she needed someone to look after Carsten. Luckily, she was able to arrange for part-time daycare at a facility set up to help single mothers.

Carsten was born with normal sight and hearing – deafness came later and was not discovered right away. One day when Carsten was on an outing at the beach with his daycare group, he got lost. The adults started searching for him, calling as they went, but he didn't respond. He was found eventually, but his caregivers wondered why he hadn't come when they called. One of them decided to take him to the doctor, who determined that Carsten was deaf. He was three years old at the time, and had become deaf a year earlier after a bout of meningitis.

Grethe and Orla consulted Dr. Ole Bentzen at the hearing center in Aarhus, who advised them not to send Carsten to a school for the deaf. He convinced them that it would be far more beneficial for Carsten to attend a regular public school in Grenaa, and they followed the doctor's advice. Fortunately for Carsten, he had a very caring teacher who wrote everything down on the

Carsten's parents, Grethe and Orla, just married in 1953

Grete and Orla Thorup at the door of Tirstrup Church, where they have just been married. The bride is wearing a long white bridal gown with a white veil over her dark hair. She is holding a large bridal bouquet in front with her right hand, with her left hand under Orla's arm. The groom is almost a head taller than his bride. He is wearing a tuxedo with white butterfly bow tie and a white boutineer.

They are both smiling broadly and look very happy indeed.

Official wedding photo. Tirstrup, 1953. Local photographer.

blackboard. He copied that into his workbook and was able to follow the class reasonably well.

In 1963 – eight years after Carsten was born – Grethe and Orla had a daughter, Lone. She was born with a slight hearing impairment, but managed fine in a regular public school.

Carsten's parents gradually noticed that although he did well enough scholastically, he had trouble making friends. They considered whether it might be better for him to have contact with other deaf children, but they worried about having to send him all the way to Aalborg, which was the closest school for the deaf. That would mean boarding at the school and only coming home on weekends. At age nine, he was still very young, but in the end, they decided to do what they thought was best for their son, and in time they could see that he flourished at Aalborg School with his new friends.

It took Carsten a while to get used to the new teaching methods. He's told me that he's never forgotten his first days at Aalborg School. He was used to writing everything down at his old school, but here students were given neither pencils nor workbooks. He looked around in confusion at his new classmates, who were all focused attentively on the teacher and the teacher's sign language. Carsten had never seen sign language before coming to Aalborg School. Despite being introduced to sign language relatively late, Carsten caught on quickly and did well in school.

Carsten was so happy living in the dorm during the week that he felt bored at home on weekends. To compensate, his grandfather began teaching him how to play chess. His grandfather wasn't a keen chess player, however, so in the end it was the father of Carsten's babysitter who taught him to play serious chess, and Carsten was hooked.

When he was older, Carsten moved to Aarhus to be near the deaf youth association, where he also played chess, and later he began taking the train to Herning, where he played in the chess club. He won many club championships, and we still have one of the challenge cups with Carsten's name engraved on it several times.

One day when Carsten was on his way home from the chess club and waiting for the train at Herning Station, a drunk wandered over to him and tried to engage him in conversation. Carsten pointed to his ears and gestured that he was deaf, and the drunk gave up and moved along to the next man. To his surprise, Carsten saw the next man copy his own gestures, with the result that the drunk again staggered off. Carsten then asked the man if he were really deaf, and the man smiled and shook his head. He had just wanted to avoid having to talk to the drunk.

In about 1983, when Carsten was in his late twenties, his sight deteriorated drastically. Carsten does not have Usher Syndrome as I do, and even today he does not know with certainly why he lost his sight.

He had started working at the weaving mill in 1976, and shortly thereafter began having episodes of blurred vision. His doctor wrote him a prescription that should have resolved the problem,

but didn't. In fact, his sight got worse, and it was discovered that his optic nerve was seriously atrophied. Carsten suspected that his medication might have worsened his eyesight and immediately stopped taking it. There was no proof, however, and the damage was irreversible.

Naturally, Carsten's deteriorating eyesight meant dramatic changes in the life he had led so far. He used to ride his bike to work from his apartment in the residence for adults with reduced physical abilities, though he was saving as much money as he could so he could move to a new apartment once he met the right girl. He was able to work at the mill for almost nine years, before he had to stop due to his failing eyesight, and was granted early-retirement status instead.

Carsten's reduced sight didn't prevent him from playing chess. Some people might wonder how it's possible to play chess without being able to see the board, but Carsten can feel the shape of the pieces and their position, and is so familiar with the board that he can calculate his next move. Besides, every square on the special board has a hole into which the pieces can be fitted so that they can't be knocked over easily.

Over the years, Carsten has participated in chess tournaments for people who are deaf, deafblind, hearing blind and hearing. He has participated in several Nordic tournaments for deafblind people in Norway, Sweden and Finland, and he won the Nordic Chess Championship when it was held in Sweden. The prize was a handcrafted marble chess set in East Indian style, in which the knights

are elephants instead of horses, and so on. It is by far the heaviest prize Carsten has ever won! When he brought it home, we put the chess pieces into a type-fitter's tray and hung it on the wall where they could be admired.

Carsten has recounted an embarrassing incident that happened when he was in Oslo taking part in the Nordic Chess Championship. At one point he was taking a walk in the city with his personal assistant, Ulla Kristensen, who is also deaf. They were strolling down a pedestrian street when Ulla noticed that everyone was staring at them. Suddenly she realized that she and Carsten were blocking the procession of a marching band that had been forced to halt behind them because they were in the way. Ulla quickly pulled Carsten out of the way. Naturally, they were both mortified. That's one of the disadvantages of two deaf people being out together, and the only thing to do is try to be extra observant.

Carsten has also participated in the European Chess Championships several times, and in 1997, it was held at Castberggård. That was the first time in the history of the Danish Deafblind Association that a European Chess Championship was held for deafblind contestants, and Carsten won!

Carsten's father died in 1999, a few years short of his Golden Wedding Anniversary, which he and Grethe would have celebrated in 2003. Although our family had grown smaller, it gave us every reason to stay close and honor family traditions.

One Christmas Eve, Carsten and I invited my sister and Grethe to join us for a traditional Danish dinner of roast pork with crack-

ling, potatoes and gravy. It reminded me of the good old days when we were children and used to celebrate Christmas with our parents. We had bought Christmas elf hats, which we expected everyone to wear during dinner. Grethe was a good sport and wore her hat all evening, not even taking it off when the taxi driver who came to pick her up did a double-take.

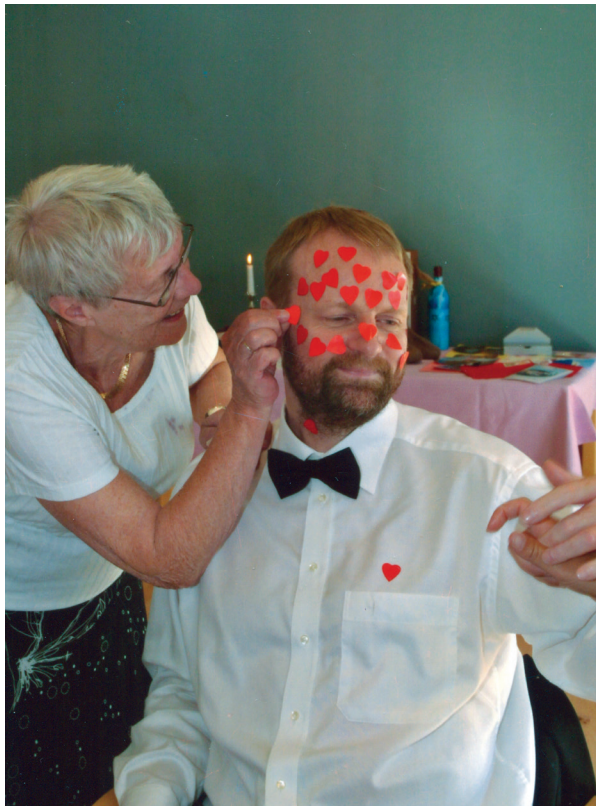
In 2005 we celebrated Carsten's fiftieth birthday by throwing a party at Fuglsang Center in Fredericia. Although there was no music or singing, we were able to hold speeches thanks to our interpreters. Wanting to do something unusual, I asked our guests to line up, then handed out tiny, self-adhesive Danish flags to the women, and small wooden clothespins with flags to the men. The idea was for the women to give Carsten a kiss and mark the spot with a flag, and for the men to touch Carsten lightly and put a clothespin on some part of his head, for example in his hair. Before long his head was fully decked with flags and clothespins, and everyone – Carsten included – had a really good time. I could tell that he was happy, and it was a memorable day for both of us.

When Carsten's mother turned eighty-five in 2011, she held a small birthday party for family and friends. She had asked for gifts of money only, and during the party she revealed that her plan was to buy a computer, so that she and Carsten could email each other. They'd been exchanging faxes for years, but it wasn't as convenient.

We were all impressed with the speed at which Grethe had learned to use the computer, and she and Carsten enjoyed being

able to communicate so easily for several years. Unfortunately, she died in 2015, the same year Carsten turned sixty.

Understandably, Carsten was not in the mood to throw a big party on his birthday that year, so we went to Bali instead as a treat for him. We both miss Grethe very much. She was a lovely, warm person and the heart of our little family.



Carsten's 50th birthday party at Fuglsang Center, 2005

Carsten wearing a white dress shirt with cufflinks and a black bow tie. Next to him is a woman guest with short gray hair and glasses wearing a white short-sleeve blouse and dark skirt. She is putting a small red heart-shaped sticker on the right side of Carsten's face on the exact spot where she kissed him. Contact communication is ongoing between Carsten's left hand and the hand of his interpreter, Annemette Branderup. Carsten appears to be enjoying contact with his guest. A table with gifts and candles can be glimpsed in the background.

Indoor color photo. Fredericia, 2005. Photographer: Kirsten Malmbak.

A close-up of Carsten's decorated face. Female guests have put red heart-shape stickers on his face, while male guests have used tiny clothespins to attach small Danish flags to his hair, eyebrows, beard, ears, bow tie and shirt. It is difficult to characterize the expression on his face, but he seems to be enjoying being the center of attention.

Indoor color photo. Fredericia, 2005. Photographer: Kirsten Malmbak.

17. Everyday life for deafblind people

Like other couples who have decided not to have children, Carsten and I have arranged our lives around the two of us. We live in an ordinary apartment and spend our time in ways that we find normal. However, our everyday life differs from that of other people, because we have to make allowances for our loss of sight and hearing.

Carsten is able to distinguish between light and shadow, while my field of vision is now limited to one or two degrees. In comparison, a person with normal eyesight has a horizontal field of vision of about 180 degrees. In addition, we are both profoundly deaf. Perhaps most people would consider our existence impossible, but we have many years of experience living through our other senses, even though it isn't always easy. We learned to cope when we lived alone, and we support each other now that we live together.

Something as seemingly insignificant as a doorbell is one example of an everyday aid. Our special doorbell sends a signal to a pocket vibrator when someone rings. People who are deaf or hard of hearing often have doorbells that activate a blinking light inside their residence, but that wouldn't work for us.

Our entryway, kitchen and living room are brightly lit with

Carsten and I enjoying Christmas vacation on Madeira in 1985

Carsten and Kirsten have their arms wrapped around each other, and their wide smiles signal their sense of partnership. They are standing near a rocky cliff coast on Madeira, with lazy Atlantic waves landing on the beach three hundred yards below them.

The sky is overcast, but both are wearing summer clothes with short sleeves. The sea is in the background, and a flat stony beach leads to tall vertical cliffs rising from the sea.

Outdoor color photo. Madeira, 1985. The photograph was taken by a German tourist couple who gave Carsten and Kirsten a taxi tour around the island.

special light fixtures. They provide indirect light that helps me see more clearly inside. Outside during the day, my eyes are extremely light sensitive, and I have to wear sunglasses.

I have a desktop computer with a large screen. To write texts, I use a program called ZoomText, which magnifies the letters. I also use a contrast function due to my light sensitivity, meaning that I write with white letters on a dark background. I print out e-mails or any other computerized text and then read them using Closed Circuit Tele Vision (CCTV), which is a magnifying reading device. It looks like a computer screen connected to a small camera focused on an adjustable table under the screen. I put the text on the table and the camera transfers it to the screen, where text size and color can be adjusted.

I can't use a smartphone, because the screen and text are far too small, but I do have a cell phone with large text so that I can send messages.

When Carsten is reading e-mails, he uses a Braille display, which is an electro-mechanical device that can be coupled to a computer or iPad. The display has up to 80 Braille units, each of which is formed by eight tiny symbols. When the user marks a piece of text on the computer screen, the tiny symbols in each unit are raised or lowered automatically, thus forming the letters into Braille, which users can then read with their fingers.

Carsten often uses the Braille display to read e-mails, text TV or news from I-deksy – a combination news and debate forum and e-mail service specifically for people who are deafblind. However,

this means that we do not get "breaking news" like people who can use smartphones, iPads, or laptops, and we are confined to our homes when we want to communicate. I used to enjoy keeping up with friends through Facebook, but since my sight worsened so dramatically after a retinal detachment in 2014, I found it difficult to use social media, much to my regret. All in all, it is difficult for people like me with visual impairment to use the Internet, but more about that later in the chapter.

Otherwise our daily lives are rather ordinary. We prepare our own meals at home, but I do need the help of a personal assistant (PA) for shopping. I don't leave home on my own anymore. Once in a while, we take a break from cooking and go out to eat with our PAs. There are many good restaurants in town, and we enjoy trying something new from time to time.

Carsten and I were more independent when our sight was better, but today we need PAs and interpreters in order to carry out our daily chores and communicate with others. Our PAs accompany and help us with errands, while our interpreters facilitate communication between us and a third party, for example, at meetings. Both PAs and interpreters communicate with us using tactile sign language, which is basically ordinary sign language, except that we put our hands inside theirs in order to feel the signs because we cannot see their hand movements or gestures. They also use a number of haptic signs made on the arms or backs of someone who is deafblind in order to provide supplementary information to sign language.

Unlike PAs, sign language interpreters do not work for us regularly. We hire them through an agency with a so-called time bank that covers the salary for interpretation at meetings and events as well as leisure activities, but does not cover private social arrangements. PAs are paid by the municipality, which sets time quotas based on an evaluation of the individual's needs

Both Carsten and I try to stay active. Carsten works out at a fitness center in the winter, and I still swim a couple times a week. We take the bus, but we need a PA to accompany us to the bus stop. I also need a female PA with me so that I can use the changing room at the swimming pool. We can manage on our own for the return trip. The bus stops near our apartment, which is luckily on a dead-end street, so we can't overshoot the mark.

Having said that, I feel compelled to add that Carsten has managed to get into trouble occasionally on his way home. The first time was one afternoon when I was doing the dishes in the kitchen and waiting for Carsten. Out the window, I could see a man walking his bicycle with one hand, and holding onto a dog on a leash with the other. He looked up at our windows, disappeared, then reappeared in the parking lot next to our kitchen window. Just then, a car pulled up and the female driver stepped out – together with Carsten. I couldn't help wondering what Carsten had gotten himself into. I watched the woman help him over to the stairs, then went out to greet them. I smiled politely at the woman and the biker – all the while wondering what was going on.

Carsten explained that he'd fallen asleep on the bus, and when

he woke, was confused and thought he'd reached his stop. He got off the bus, but soon realized it was the wrong stop and that he was in unfamiliar territory. He felt he had no choice but to wave his white cane around and hope someone would see it as a cry for help. A biker stopped and as luck would have it, Carsten was carrying his card with our address on it. We're supposed to have the card with us when we go out in case we get lost or need a taxi. Unfortunately, the biker wasn't familiar with our street, so he stopped a car to ask for further directions. The driver knew where our street was and offered to drive Carsten home. Carsten felt safe the moment he got in the car, because he intuitively felt he'd be delivered right to his door. He was lucky to meet two such kind people who understood, without a word being spoken, that he needed help.

He had a second experience much like the first. Once again, he was on his way home from fitness and fell asleep on the bus. This time, however, he didn't wake up until he felt the bus's engine stop. He knew at once that he'd reached the end of the line. He got off the bus and tried to show his address card to the people around him, but no one offered to accompany him or put him on another bus. He stood there for a long time before someone finally put him in a car and drove him home. Meanwhile, back at our apartment, I was surprised to see a police car pull up outside. I went out and watched Carsten get out of the car, while two policemen smiled at me. When I told Carsten that he'd been driven home by the police, he was flabbergasted.

Even though we live on a quiet dead-end street, which we know inside and out, accidents can still happen. Lacking the royal senses limits our ability to orient ourselves in relation to our surroundings, and we rely on others to notice and help us if necessary. One day in the beginning of June 2011, I had been out shopping (my residual sight still good enough in those days for me to go shopping without a PA), and I had almost reached home carrying two shopping bags, when everything went black. I don't remember what happened, but when I regained consciousness, I found myself, to my surprise, lying in the parking lot looking up at two horrified women with their hands clapped to their mouths. At first I didn't realize what had happened and I felt no pain, but when I looked down at my leg, I suddenly understood why the women were upset. My lower left leg was bent at almost a 90 degree angle, and I realized I must have been hit by a car. One of the women had backed into me in the parking lot outside our apartment, so at least it was a mercy that the accident happened so close to home.

Fortunately, I knew both women well, as they were my neighbors. When I realized that they were calling an ambulance, I gestured for them to wait. I didn't want to leave without giving Carsten a message to let him know what had happened. While my neighbors looked on in astonishment, I bent my broken leg back into place, then dragged myself over to the sidewalk. by putting my broken left leg over my right leg, taking off my shoes, putting them on my hands, turning over and pulling myself across the asphalt with my arms. But I couldn't get myself up the stairs, so waited while the two

women called on a third neighbor who knew a bit of sign language. I gave the third neighbor my key and signed her to fetch Carsten. Imagine his surprise when a strange woman suddenly let herself in the apartment and took hold of his arm. He knew it wasn't me, so he asked where I was using sign language, and the woman signed back as best she could with the sign for "fall." Carsten understood the message at once and hurried downstairs, where he found me sitting on the curb. He seated himself beside me so we could communicate, and I explained what had happened.

At last an ambulance and a police car arrived on the scene. The paramedics put a bag on my leg and pumped it up to keep it stable, as I have seen them do for injured skiers. I led Carsten's hands to the bag on my leg, so he could follow what was happening. Then I asked him to keep his pocket vibrator with him at all times, in case someone rang the doorbell to get in touch with him. Then I asked one of my neighbors to take my shopping bags up to the kitchen and unpack them.

Once that was taken care of, I could in all good conscience let the paramedics carry me into the ambulance and drive to the hospital. They took me to the trauma center at Aarhus University Hospital, where an interpreter was waiting to help me. By law, interpreters are not called to the scene of an accident, but are present only at the hospital when an injured person is brought in. It would have been useful to have had an interpreter on the scene of my accident, but of course, it was a great comfort to have one by my side at the hospital.

A little while later, the police came to the hospital and explained through the interpreter that my neighbor had been given a hefty fine for negligence and penalty points had been put on her driving record, because she had backed out of the parking space without checking her mirrors and thus had failed to see me.

My neighbor came to the hospital with a bouquet of flowers and told me how very sorry she was to have caused the accident. I bore her no ill will and when I said: "What's done is done," I could sense her relief. She hugged me and promised to bring Carsten and his PA to visit me the next day.

When a doctor finally examined me, he said that because of my age, the fracture wouldn't heal with just a plaster cast. Instead, the bone would have to be secured with metal plates, which was a more extensive procedure. I was sent to the operating room and woke up in the ICU.

The next day I realized that my sister had sent me several text messages and was wondering why I hadn't replied. Of course, I hastened to reassure her.

As soon as I could, I asked a nurse to call an interpreter so that I could communicate with the doctor. However, she categorically refused to send for another interpreter. Her reasoning was that I had been assisted by an interpreter the day before, so that if I now wanted additional help, I would have to arrange and pay for it myself. I let her know that I didn't agree, but she stood her ground, and in the end I was forced to make my own arrangements.

When the interpreter arrived, she and the nurse had a long

conversation in which I was not involved. According to the interpreter, the nurse had said that I was being unreasonable. Naturally, her remark did little to improve my mood, so I asked the interpreter to tell her that I wanted to go home immediately, because I had had more than enough of her and didn't want to stay in the hospital another minute.

Just then Carsten arrived in the company of his PA and our neighbor, and I repeated my message to him. He was surprised that I wanted to come home so soon, but when I explained why, I could sense his relief.

Not long after my return home, I decided to write an article for the Danish Deafblind Association's magazine about the episode with the nurse. The article ran under the headline: "Hospital Fails to follow Interpreter Legislation." As a result, the hospital sent an apology and reimbursed me for the interpreter's hours. I was relieved, of course, but still upset that all the commotion had been necessary.

In fact, my experience could have been much worse. Only a few years earlier – before a Social Interpretation Project came into being – Danish hospitals did not routinely provide an interpreter when a deaf patient was admitted. With the exception of planned operations, deaf patients often found themselves admitted and treated without being able to explain their predicament or understand the procedure, which must have been frightening. It would be like being admitted to a hospital in a foreign country, where you were unable to communicate with the people taking care of

you. Fortunately, deaf patients today have the right to assistance from an interpreter when hospitalized, but even after the Social Interpretation Project was completed in 2009, there was still a certain amount of confusion about the new legislation, and it took some time before the new rules became standard practice in Danish hospitals.

So there I was in 2011, vice chairman and still very involved in the work of the Danish Deafblind Association, and now laid low by a broken leg. The annual meeting was held soon afterwards, and even though I was in a wheelchair by then, I was forced, to my great irritation, to stay home. During the election for chairman, a Skype connection was set up so that I could follow the meeting and others could see me on a big screen. I was elected chairman, but was very sorry I hadn't been able to be there in person.

After a few weeks at home, I was able to go outside using crutches or a walker, but was still not as mobile as usual. The Danish Deafblind Association had planned a trip to Finland in August in connection with the European Deafblind Culture and Vacation Week, and in my new role as chairman, it was important for me to attend as a representative of our association. I was bound and determined to go, but was unable to manage with crutches alone, so had to order a wheelchair at the airport in Copenhagen and the hotel in Finland. Fortunately, the PA who accompanied me was able to push my wheelchair, so I managed to make the trip.

Traveling by taxi can also be challenging for deafblind people. We do carry a card with our address on it so at least the driver

knows where to go, but we can't see the amount on the taximeter at the end of a ride, so we always ask the driver to "write" the amount in our palm using a finger. We once had a taxi driver who couldn't figure out what we meant, and wrote the fare on Carsten's hand with a pen. You can't help wondering how the driver thought this would be any help to a blind man.

I often depend on taxis to take me wherever I need to go. One morning I was waiting for a taxi to take me to the train station. I had ordered it by e-mail as usual, and the order had been confirmed, but the taxi didn't arrive. When that happens, most people call the taxi company to find out what the problem is, but that option was not open to me. Nor could I send a text message. I'm quite capable of texting, but taxi firms don't accept texting as a form of communication, and no exceptions are made for deaf people. So I knocked on my neighbor's door and asked him to call the company for me. After a long conversation, my neighbor simply nodded at me to indicate that the taxi was on its way. By this time I was getting anxious, but the taxi finally arrived, and thanks to the driver's speed, I made my train.

When I got back home, I had an e-mail from my neighbor, describing his long conversation with the taxi firm. Evidently the dispatcher had sent a taxi to the right address – but in the wrong town!

The same thing happened again, but this time the taxi was in the right town and on the right street, but had driven to number 14 instead of 140. When it happened for a third time in six months,

I'd had enough. I hated having to knock on my neighbor's door and ask him to sort out my taxi problem, so I wrote an e-mail to the taxi firm to complain that they didn't honor their agreements, and asked them to pass on my e-mail to management. I received an apology and a promise that it would never happen again. I had to be content with that, and yet I think it's unreasonable of them not to make an exception for deaf people and allow them to text a taxi firm. What are we supposed to do if there's no one to make the call for us and no time to send an e-mail?

While I still had a fair amount of residual sight, I enjoyed reading the newspaper, especially our local afternoon paper. One day when I was out, Carsten decided to pick up the paper from our mailbox and wait for me on the stairs. He walked down to the mailbox and was pleasantly surprised to find me arriving at the same time. He gave me a kiss – or at least he thought he had until he realized that he had kissed the newspaper delivery person instead! He was horrified and hurried back up the stairs. He recounted the episode when I got home, and confessed that he hadn't been so embarrassed in years. We don't know who delivered the paper that day, or even if it was a girl or a boy, but I'm sure whoever it was remembers the incident to this day.

Our local paper later became a morning paper, which I enjoyed reading at breakfast time. But as my sight deteriorated, I had to give up reading altogether. The last time I read a newspaper in physical form was in about 2008. Although I usually follow the news these days through I-deksy, I still miss reading about my local area. We

sometimes ask our PAs to look for breaking news on their smartphones, and they pass it on to us using tactile sign language.

As I've mentioned earlier, I-deksy is a program developed for people who are deafblind. It consists of an e-mail service and a news and debate forum, but also makes it possible for us to get news from either the main Danish television station or text TV. In fact, I-deksy has everything a deafblind person needs to stay connected and up-to-date with the world, so it is an enormously important tool in our everyday lives. It was a serious blow for many of us when it suddenly stopped one day in 2017. The problem was not a minor glitch that could be fixed in a day or two, but a major breakdown that lasted for two months, as one team of IT technicians after another tried to get the program working again. They succeeded at last, but the patience of those of us who are deafblind was certainly put to the test. Imagine what it would be like to be without the internet and your phone for two months. Most people would feel completely cut off from the world and without any means of direct communication. That's what it was like for those of us who are deafblind, as many of us depend solely on e-mail for communication. The problem also affected the families of deafblind people. For example, Carsten's sister couldn't understand why she hadn't heard from him. Fortunately I was able to text her as well as my sister, and we were able to stay in touch.

I thought a lot about my sister and others who live alone. They must have felt incredibly isolated, especially over the ensuing holidays, when their PAs were not available. At least Carsten and I

have each other. The program was eventually repaired, but it was an extremely frustrating period for all of us who are deafblind, and it shows how vulnerable we with our double loss of senses are with regard to contact with the rest of the world.

Although the months without I-deksy illustrated our dependence on technology, today we who are deafblind are facing far more critical challenges from administrative changes being made in municipalities since 2007. Under these reforms, the existing 271 municipalities were reduced to 98, and the 14 counties were converted into five regions. Responsibility for the specialized help needed by those with disabilities was transferred from a centralized governmental agency to the municipalities. The idea was that people with disabilities would benefit more from specialized help in their own community, and would therefore be able to lead an easier, more normal existence. However, ten years after this restructuring, many handicapped people and others with special needs have found that it has not only led to less support, but has actually made their daily lives more difficult.

I know this is the case for several people in my circle of friends, including my sister, who lives in a different municipality. Unfortunately, the amount of support granted to those with handicaps varies from person to person and from municipality to municipality. Those of us who are deafblind are allocated a certain number of hours a year to hire a personal assistant. Unfortunately, the number of Anne's PA hours has been slashed, so that she doesn't have enough help with her daily chores.

Anne would like to be able to leave her house three times a week to shop or go for a walk, in keeping with the Danish Health Authority's recommendation on physical activity. With the lower number of PA hours now allocated to her, this is impossible. Her doctor has also recommended that she see a physical therapist, but if she doesn't have enough assistance to help her with grocery shopping, she clearly can't see a physical therapist either.

Despite her doctor's recommendations, the municipality refuses to allocate more hours to Anne. She has sent me many texts complaining about her situation and telling me how isolated she feels. They are painful reading, and I know she's not the only deafblind person in this situation. The indifference shown to the needs of deafblind people astonishes me. I also don't understand why there are so many regional differences. While I don't have the same problems as Anne, why should she have to move to another municipality in order to get similar, reasonable treatment? The proponents of restructuring point out that it allows more handicapped people to be helped in their own homes, rather than being institutionalized. However, this is scant comfort for the individuals whose rights have been trampled on in the process.

Furthermore, a change in the 2014 Consolidation Act on Social Services has led to large cutbacks in the handicap sector, which means we can no longer use PA hours for courses at Castberggård. These courses have been a long tradition for deafblind people and have played an important role in maintaining social networks as well as giving deafblind people a welcome break from daily life.

All this was ended abruptly, however, and Castberggård has been forced to cancel several courses due to lack of applicants – a great loss for those who were looking forward summer courses and other Castberggård events.

One of those courses, which was held several times at Castberggård, is "Deaf people at work." It has been of great benefit to many, since it deals with the rights and regulations deaf people are likely to encounter in work situations, and also teaches them how to maximize their own knowledge and skills. Making your way on the job market can be a complicated affair for deaf people. Many of them are able and willing to take subsidized jobs, but are only eligible after a long prior period of prior illness. So regardless of whether a doctor has declared that the person is able to work, the rules must be followed. No exceptions are made, which means an unnecessary and expensive waiting period, as the municipality must pay a disability benefit to the deaf person in the meantime. Support for personal assistance has also been curtailed, so the system is illogical and counterproductive. Case processing also takes longer due to cutbacks in municipalities and job centers. This is a frustrating situation for deaf people, who merely want to be good, useful citizens.

In 2016, the Danish Deafblind Association's chairman, Bjarne Hvidsten, fired off a press release, in which he expressed his frustration at the increasing isolation of deafblind people resulting from these cutbacks. Impacted areas include something as basic as transportation, with deafblind people not being offered

handicap transportation despite the hurdles they face using public transportation. He also emphasized how the cutbacks in the hours allocated for PAs and interpreters further isolate deafblind people.

For example, Bjarne himself is politically active and wants to stay on top of current events, but has not been allocated enough interpreter hours to be able to follow some of the important political coverage on TV. Predicaments such as these make deafblind people feel like second-class citizens.

Municipalities do make allowances for us in one way: They send us letters by mail instead of digitally. While the municipality, the tax department and banks are required to communicate electronically these days, we get actual paper letters. This is a big help, as the websites of these agencies and companies are not easy for a deafblind person to navigate. Although we can't read paper letters directly, we can read them using CCTV, or our PAs can sign them for us.

Unfortunately, many other websites create similar problems, as access for deafblind people is rarely considered by designers. I can't use search engines to surf on the net for the same reason.

I hope that one day it will be possible to develop websites that are easier for people who are deafblind or visually impaired to use. It would mean so much to us to have access to information on the net, to be able to pay bills using electronic banking or to order groceries or various consumer products.

I recently received an e-mail from Nota – an online library for

people with reading difficulties – with the information that it was now possible to access audio books via a new text-to-speech app. I replied that it wouldn't be of any use to me, since I'm deaf. But I do think it's a fine option for blind people who can hear.

In general, I'm impressed at the speed of technological development in recent years, and can only hope that it will be of increasing benefit to deafblind people. Braille display is a good example of a technological aid that has definitely made life easier for people who are blind or deafblind, but there are too few examples of this kind. The Danish Deafblind Association has been left on its own to work with IT technicians to develop and pay for new aids. Obviously, that is a slow and expensive process that will stretch well into the future. We lack the know-how and vision needed to develop technology that can help deafblind people enjoy a more normal daily life.

Whenever I take the train, I notice other people sitting glued to their smartphones. I would do the same if I could, but at least I always have a PA with me and can ask her to find some news for me on her phone.

When the conductors make their rounds, passengers either show them the paper tickets they've printed out at home or display the e-tickets on their smartphones. Owing to the poor accessibility of the railway company's website (and I'm not singling them out for disgrace, as poor website accessibility is a problem everywhere), this is yet one more thing that I can't do. Instead I buy my ticket at the ticket office, and I sincerely hope this service

won't be discontinued one day for lack of customers. Not being able to make use of the latest technological trends is not a position anyone wants to be in, as I'm sure many elderly people can testify.

At the end of the 1990s, Carsten was granted a combination scanner-reader called OPUS, in which a typewritten document is placed in the machine, scanned and converted to Braille. This is an example of how the system worked before local government restructuring. The machine cost about 12,000 dollars, but it was considered a necessary aid for Carsten. When it stopped working in 2012, we asked our municipality for a new one, but our request was denied on the grounds that it was too expensive. Instead we were offered a cheap alternative. The new scanner was not as easy to use, since it first had to be connected to the computer, which in turn had to be connected to a Braille display. In other words, three separate electronic systems had to be put to use, while OPUS was a single unit. We never managed to get the scanner to work with the computer, and ended up sending it back. Nowadays I-deksy provides us with an excellent solution, since it allows Carsten to receive documents by e-mail and then read them on his Braille display.

OPUS was somewhat of a sensation at the time, and, in fact, the Danish Deaf Film Company came to our apartment to document its impact on Carsten's daily life. The same film company has approached us for various other productions, and we're grateful to them for including deafblind people in their focus.

For people who are deaf, there are fairly good opportunities

to follow programs on TV. In addition to subtitling, there's a sign language channel and a sign language program on another channel, which I used to enjoy watching. Now that my sight isn't good enough, I follow the program on text TV, and am glad to have that option.

So how is life for people who are deafblind? I would say that it's *possible*. We manage with the aids at our disposal, with help from interpreters and personal assistants, and with the support of the Danish Deafblind Association. Feeling that you're part of a community is immensely important to people who risk being isolated because of a handicap. This sense of community is one of the things we get out of our membership in the Danish Deafblind Association, along with the practical support and information that make our daily lives easier. Still, we can't exist in a bell jar, cut off from our surroundings. Accessibility is key to equal treatment, and I'm not just referring to the internet, but also accessibility with respect to public spaces and transportation. These are key areas in which too little consideration is given to the needs of people who are deafblind.

Travel is one area open to people who are deafblind, and that leads me to the next chapter.

18. To travel is to live

I heartily endorse Hans Christian Andersen's famous line that to travel is to live, and travel has certainly had a great impact on my life. Friends once told me they are astonished at the number of trips Carsten and I have taken. I had to remind them that we don't lead the same kind of lives they do. While they have a family life with children, pets, houses, gardens and cars, we have none of those things. Our travel experiences help give substance to our lives.

Nonetheless, many people can't understand what we get out of travel since we can neither see nor hear. The answer is that we experience the world through our other senses: touch, smell and taste. I think people would be surprised at the many impressions we absorb through those three senses. When we're in a new place, we sense changes in the air, smell new aromas and explore interesting objects with our hands, not to mention the powerful sensory experience of eating foreign food. We fully utilize the senses we have, and perhaps appreciate things other people take for granted. For example, I remember the contrast between a restaurant we visited in China and another one in Greece. It wasn't just the smells, sounds and food that were different, but something as relatively unremarkable as the furniture. The high-backed Chinese

Meeting a new friend? The Canary Islands, 1987

Carsten is holding a half-grown chimpanse that is clinging to his chest. His right hand is supporting the chimpanse's back, while his left hand is exploring its neck and shoulder. Carsten is dressed for summer in a white GI jungle hat, short-sleeve light blue t-shirt and checkered slacks. Carsten's facial expression and hands indicate that he is gaining an impression of the chimpanse. Kirsten is standing in the background. She is wearing glasses, white shorts and a short-sleeve blouse. Her smile is full of pleasure as she observes this scene of intimate contact between man and animal.

Outdoor color photo. Canary Islands, 1987. Photo: tourist photograph.

chairs were intricately carved in dark wood, while the low-backed Greek chairs were in light wood with webbed seats. We place a value on those types of details, so perhaps the world we sense involves experiences that are different from those of other people.

We are also helped by our personal assistants (PAs), who are very good at describing our surroundings so that we have a good idea of where we are. Until my unfortunate retinal detachment in 2014, I had fairly good residual sight, so despite everything, I've been greatly enriched by vast numbers of sensory impressions from our travels.

In the following, I want to relate some of the cultural, personal and sensory experiences Carsten and I have had as deafblind travelers, and what they've meant to us.

Early travels

In the 1980s, when both Carsten and I had more residual sight, we felt comfortable traveling on our own without PAs, and we went on organized tours just like our fellow travelers who could see and hear. Travel companies established especially for people who are deaf and hard of hearing came later.

Over Christmas in 1985, we took an unforgettable trip to Madeira with Tjæreborg Travel. One afternoon our tour group stopped at a restaurant to eat. Our tour guide came to over to our table with a message from another couple in our group, who wanted us to go touring with them the following day. We were

surprised and delighted at the invitation, which we readily accepted.

We had agreed to meet the couple at our hotel the next morning, and were anxious to find out what they were like. They turned out to be a Danish woman and her German husband. We thanked them in person for their invitation. They had arranged for a taxi tour of the island, and had hired a driver who was knowledgeable about the local high points. Carsten and I got on well with the other couple. Since we weren't traveling with PAs, we communicated using gestures, plus the woman and I wrote notes back and forth. The husband turned out to be rather athletic, at one point even lifting Carsten onto his back and carrying him around. The taxi driver shook his head at their antics.

In the evening, we found a nice restaurant where the four of us and the driver ate dinner. We had a thoroughly successful day, and I thought it was a lovely gesture for the other couple to have invited us. Not only were they not anxious about spending an entire day in the company of a deafblind couple, they had apparently felt that we deserved an extra treat because of our handicap. When we got back to our hotel, Carsten tried to pay for our share of the expenses, but they wouldn't hear of it, claiming that it had been their pleasure to have us join them. Carsten and I were both surprised and touched by their generosity.

At noon the next day, which was Christmas Eve, Carsten presented me with a small gift-wrapped box. I asked him if he didn't want to wait until evening to exchange presents, but he insisted

that I open his at exactly twelve o'clock. I couldn't understand why it was so important to him, but did as he asked, and was astonished when I opened the box to find a beautiful engagement ring. At that point we hadn't even started living together yet, much less discussed marriage. He'd taken me by surprise, but of course I said yes!

Afterwards, Carsten confessed that he'd told his friends about his plan and they had urged caution. Our relationship was in its early days, and what if I were to say no? Carsten assured them that he was positive I would accept his proposal, which indeed I did! I was impressed by his confidence in me and in our relationship. So I can now say that we were engaged at twelve noon on December 24, 1985.

That same evening we had Christmas dinner with the other people in our group, and the travel company gave each of us a gift: a knitted cap embroidered with tiny figures and the word "Madeira." Naturally we've kept our caps all these years to remind us of our special day.

For many years, we celebrated every other Christmas abroad, on Spanish islands in particular. In the years we weren't traveling, we spent Christmas with our families.

In 1987, we traveled to Gambia, still without personal assistants. We were members of the Friends of The Gambia Association, which is what had prompted the trip. Gambia also had a school for the deaf that we wanted to visit. Once more we traveled with Tjæreborg Travel, but not as part of a group tour, which

meant we had to do all the planning ourselves. The trip went well, and I was able to communicate with our Danish travel guide in writing, and to write in English when I needed to send a message to the hotel reception desk. So we were confident then about traveling on our own and used to taking care of ourselves.

A year or so later, however, we began to feel that our deteriorating vision made it impossible for us to justify travelling without personal assistants. It was not an easy decision, but it proved to be the right one. Our subsequent trips in the company of PAs gave us the security we needed to be able to devote ourselves to the experiences that awaited us.

Travel for deaf people

A travel agency specializing in arranging group travel for people who are deaf or hard of hearing was established in 1999. SignTours was started by Jan Thomsen, the hearing son of deaf parents, together with Kenneth Nielsen, who is hard of hearing.

Kenneth served as the travel guide for the agency and went on all trips. The deaf community welcomed the initiative, which gave us the opportunity to travel in a way that made it safer for us to explore the world.

In 2005, Carsten and I went on a cruise with SignTours to the West Indies with a group of other deaf people, two sign language interpreters, and Kenneth Nielsen as travel guide. Naturally, the cruise was not limited to deaf people – it would have been impos-

sible to find enough passengers. We were simply a group of deaf people taking part in an otherwise ordinary cruise, and had to follow the same routine as everyone else.

Our first challenge was taking part in a safety drill before the ship even left the harbor. We were instructed to take our lifejackets out of the closets in our cabins, and then to walk up ten flights of stairs to an assembly point next to the lifeboats. With the help of our PAs, we deaf and deafblind passengers were able to carry out the drill almost as quickly as the others. Once we reached the assembly point, we were lined up according to the location of our cabins and told to wait. We must have been at least 2,000 people gathered on the deck. Eventually, it was announced that the exercise was over and we could return to our cabins.

One special consideration had been made for our travel group. Our cabins contained a portable room kit with visual-tactile alerts for doorbells, telephone, alarm clock, and smoke detectors. We had never seen anything like it, but learned that U.S. law mandated this type of equipment on cruise ships and in hotels.

We were assigned to a dining table with the same group of people all week, and we also had the same waiter every evening. That gave us an opportunity to get better acquainted with our fellow diners, which raised our comfort level.

We had several ports of call underway, including Key West, which had suffered severe flooding during a hurricane the year before. I saw some unnatural sandbanks that had been formed by the masses of water and bore witness to the dramatic events.

In December 2007, we took a Christmas cruise on the Rhine in Germany. It was enchanting to glide down the river, with its banks rising on either side. On the last night of the cruise, passengers dressed up in their best for dinner. The dining room was almost completely full when Carsten and I arrived, but we managed to find two seats next to an interpreter and two travel guides. It didn't take long for us to realize that we had seated ourselves at the captain's table. Fortunately, the captain was welcoming and understanding. He launched into a conversation with Carsten that was so long that the poor interpreter really had his work cut out for him. The captain normally excuses himself early so he can get back to work, but on this night he stayed longer in order to talk to us, which I thought was lovely.

My friend Ulla turned 60 during the cruise. At dinner on her birthday, the waiters trooped in asking for the birthday girl. We all pointed at Ulla, but they refused to believe us – insisting that she didn't look a day over 40! The waiters went over to congratulate her, and to our surprise also wished us a Merry Christmas in sign language. A couple of the passengers had secretly taught the waiters a few signs, and their gesture made us so happy that we burst into song in sign language.

In 2008, I found myself once again on a cruise ship, this time to Bergen, Norway, with SignTours to visit the city's deaf association. The association meets in a former church, which had been repurposed as their headquarters. It is a lovely building with a welcoming atmosphere.

On that same cruise, a woman from my group told me that one of the hearing passengers had asked her a rather offensive question. Once again, this was a cruise for both hearing and deaf people, and a popular pastime was to sit on deck and read. We deaf people preferred talking to reading, and that had evidently been noticed by the hearing passenger. She hadn't seen any of us on deck with a book, so asked the woman from my group whether deaf people didn't know how to read. The woman from my group retorted huffily that if we hadn't been able to read, we wouldn't have known about the trip!

Carsten's travels

SignTours also arranged long-distance tours to Thailand, Mexico and Vietnam, which Carsten took without me, because I had to attend to my voluntary work with the Danish Deafblind Association.

I clearly remember waiting for Carsten at the train station after his trip to Mexico. I met a woman who was hard of hearing, and mentioned that I was waiting for my deafblind partner, who had been in Mexico. She said that she didn't understand how Carsten could benefit from the trip because of his "handicap". I was flabbergasted. I couldn't respond on Carsten's behalf, because he hadn't yet arrived, and I really didn't know how to answer her.

When we were back home, Carsten told me about his adventures with great enthusiasm – how he had climbed the famous step-pyramid El Castillo, in the Maya ruins of Chichen Itza – and

I was convinced that the woman at the train station had been wrong. She didn't understand how deafblind people perceive the world, and I decided that it was her problem rather than mine and Carsten's. Even though I know that I shouldn't pay any attention to the preconceived ideas of others, it isn't pleasant to be confronted with them.

In 2007, Carsten went to Vietnam with his PA Annemette. I made a cardboard map for him, marking the route with sticker dots that he could feel with his fingers and writing the names of towns in Braille.

When Carsten came home again, his biggest topic of conversation wasn't his wonderful adventures in Vietnam, but of having met the Danish Prime Minister Anders Fogh Rasmussen at the airport before his departure. Annemette had caught sight of Rasmussen, who appeared to be on a charm offensive at the airport prior to an upcoming election. She urged Carsten to go over and say something to the Prime Minister, but Carsten was reluctant, fearing that he wouldn't know what to say. Annemette convinced him to just be his usual self. With Annemette as interpreter, the two men did have a conversation. Carsten asked Rasmussen if he'd ever been to Vietnam. The Prime Minister replied that he hadn't and wished Carsten a good journey.

I found Carsten's story amusing. It just goes to show that you don't always have to travel to the other side of the world to find a challenge. It can be enough to simply start a conversation with a stranger in an airport.

Sensory experiences in Dubai

Carsten and I were quick to sign up for the 2012 Dubai tour. We visited the famous Burj Khalifa, at 2,722 feet the tallest building in the world. The elevator whisked us up to the observation deck on the 124th floor in just one minute. We could feel the rapid acceleration – it was like being shot from a canon!

We also visited the Mall of the Emirates, one of the biggest malls in the world, with a multitude of entertainments including a giant indoor ski slope with adjoining snow park. Surrounded entirely by glass, the ski area was cooled to about 28 degrees F, in contrast to about 75 degrees F in the rest of the mall. While our personal assistants and I watched the skiers on the slopes, Carsten was drawn to the cold air coming from the windows. He wanted to go into the ski area to feel the cold, but we weren't sure that non-skiers would be allowed in. Carsten's PA explained the situation to someone in the ticket office, who asked us to wait. Before long a man came back with four down jackets, which we took to be permission to enter.

We stepped into the winter landscape in sandals and borrowed jackets, which must have looked quite comical. However, feeling the cold and letting the artificial snow run between his fingers was a precious sensory experience for Carsten. How exciting to experience this wintery world in the middle of the desert!

New Zealand

After resigning as chairman of the Danish Deafblind Association in 2013, I had a lot more free time, so Carsten suggested that we travel to New Zealand the following year. I was hesitant at first about the long flight, but as Carsten pointed out, it wasn't that I was pressed for time. So I agreed, though largely to make him happy.

When the departure day finally arrived and we met the rest of the group at Copenhagen's airport, I asked the others why they had decided to make this long journey. Most said that going to New Zealand was a lifetime dream. While I'm sure that for many people a trip to New Zealand or Australia is a dream come true, it had never been my dream.

The trip lasted almost three weeks. First we flew to Australia, where we were given a tour of the world-famous opera house in Sydney, designed by Danish architect Jørn Utzon. We felt small indeed beside that grand structure with its white sail-shaped roof. Next we flew to New Zealand, where we traveled by bus for the next two weeks, staying in fourteen different hotels.

Our guide was unfortunately not used to being around deaf people, and she didn't understand how Kenneth could speak even though he was hard of hearing.

At that time, the beginning of 2014, my residual sight was fairly good, with about five degrees of fairly clear peripheral vision. Five degrees isn't much, but it was enough to provide me with some

excellent visual impressions. For example, we visited the revolving restaurant in Auckland, a narrow tower rising more than 1000 feet above the city. The restaurant is located in the upper part of the tower at about 600 feet, and rotates 360 degrees every hour. The view was magnificent, even in the evening, with the city's endless lights twinkling in the darkness. I'm grateful that I was still able to enjoy a tiny bit of that enchanting sight.

One of our stops was in a town called Mandeville, where it's possible to take an adventure tour in a restored classic airplane. I had the unique opportunity to fly in a tiny propeller airplane from the 1930s. The view was fantastic, but what I particularly enjoyed was feeling the fresh air streaming past me, and thinking all the while of all the old movies I've seen with actors sitting in these same types of planes. I never dreamed I'd ever find myself flying in one.

We also visited a deaf association, whose facilities made a big impression on me. The building was beautifully lit and had a bar where people could meet and socialize. There was also a section for young deaf people to meet and make pizzas, for example. I wished that we could have the same facilities back in Denmark. We could learn from New Zealand on that point.

All in all, the trip exceeded my expectations. I had so many wonderful experiences that I had to admit that – for both Carsten and me – it had been a dream come true.

Back in Denmark I gave a lecture about the New Zealand trip to two clubs for deaf retirees and an organization for handicapped

people. At the latter event, my presentation was facilitated by a sign language interpreter. I was overwhelmed by the large turnout of deaf and deafblind people. It meant a lot to me that so many people felt that they had got something out of my travel account.

China, my dream destination

I had dreamed of going to China ever since I was a little girl, and Carsten and I made the dream come true in 1992. This popular trip was arranged by the Danish Deafblind Association's travel committee, and I wrote three articles about our experiences for the association's magazine after we got home. A photo I had taken at Tiananmen Square of twin Chinese girls – just like my sister and me – was printed on the front page of one of the magazines. China's one-child policy was still in force at the time, but parents of twins were allowed to keep both children.

The day we visited Tiananmen Square, a long line had formed in front of the Mausoleum of Mao Zedong to see his embalmed body in its glass coffin. Members of our group were divided on the question of whether we should join the line, with some people eager and others, like me, certain it wouldn't be worth the wait. It was a beautiful day and there were lots of other options. When the Mausoleum party finally returned, I asked them what Chairman Mao looked like and the response was: "His face looked like it was made of marzipan."

Naturally, we made the obligatory pilgrimage to the Great Wall

of China. The wall is built with small towers at intervals. On top of one of these towers a man was beating a barrel-shaped drum – a reenactment of an ancient method of warning of an enemy approach. Guards down the line would begin beating their drums to signal the next tower and so on. When we climbed the tower to take a closer look, the drummer invited Carsten to beat the drum. He enjoyed pounding on the drum and feelings its vibrations, and I was pleased that he had such an unexpected opportunity to sense something new and different.

We had planned a visit to a deaf association in Beijing, but as it turned out, we found ourselves visiting a very hospitable but lone deaf person. We then asked the hotel for help in finding the deaf association. We made an appointment, only to discover after we arrived that we had been directed to a handicap center. It seems that a deaf association did in fact exist and that it had arranged for us to meet a few deaf individuals at the handicap center. They had been given time off for the occasion, which might account for their willingness to some extent.

At any rate, it wasn't difficult to communicate with the deaf Chinese using international sign language. They told us about the kind of jobs deaf people have in China, and my impression was that few of them were unemployed. For example, dental or computer technicians were trained through the Chinese Handicap Association. Many deaf people also worked in perfume, glove and shoe factories. These factories could have up to 4,000 employees, of which 600 or so were deaf. The deaf factory workers had such a

good social life that they had never considered establishing a deaf association. However, they did have a sports association for deaf people like we do, and they also put on theatrical performances in order to bring deaf and hearing people together through cultural events. Our meeting with the deaf Chinese at the handicap center was extremely educational, and is a treasured memory.

Hawaii, Carsten's dream

An extraordinary sensory experience was in store for Carsten when we traveled to Hawaii to swim with dolphins in 1999. Our personal assistants on the tour were Charlotte Dohm, who made all the arrangements for us, and her mother Grethe.

When we arrived on Hawaii, we rented a car and drove directly to a Bed & Breakfast that we had booked for a few days, a much cheaper option than staying in the island's very expensive hotels. Our accommodations were cozy and comfortable, with breakfast served on the terrace. We were introduced to a type of melon none of us had ever tasted before.

The day for our visit to the dolphin park finally arrived, and yet there was no guarantee that Carsten would be able to swim with the animals. A system of drawing lots had been introduced to protect the dolphins from too much contact. After the instructors drew the lots, the winners would be allowed to pay $100 for close contact with the dolphins. Unfortunately, Carsten's lot was not drawn, but when the instructors realized he was deafblind, they offered

to let him swim with the dolphins, free of charge. He and Charlotte were then sent off to wash their feet and don protective vests. After that they were escorted to a shallow lake, in which two or three dolphins were swimming around. In the meantime, Grethe and I and the other visitors had positioned ourselves on a bridge so we could follow what was happening below. An instructor told Carsten what to do, and Charlotte converted his instructions into tactile sign language. At one point Carsten was instructed to try and kiss one of the dolphins. The dolphin might have been confused by not being able to establish eye contact with Carsten, but at any rate they only managed an air kiss. In any case, Carsten's long-held dream of touching a dolphin came true, and he was so ecstatic afterwards that he vowed to do it again some day.

Dolphins in Israel

A year later, in 2000, Carsten had his second meeting with dolphins, this time at the Red Sea in Israel. Once again, Charlotte and her mother Grethe accompanied us.

The dolphins had originally come from the Black Sea, where they were part of the Soviet military program. They had been trained to localize sea mines and to rescue military personnel in distress at sea. The U.S. had had the same program since the 1960s, and dolphins are still being trained to carry out military objectives.

However, after the collapse of the Soviet Union at the start of

the 1990s, the Soviet dolphin training program was abandoned, and the dolphins were moved to the Red Sea. Some people wondered if these could really be the same dolphins, but we were informed that dolphins live an average of twenty-five years, with some growing as old as forty. The dolphins were able to roam quite freely. The dolphin reef was surrounded by nets, but they had access to the open sea. The dolphins returned often to the "safe" area behind the net, because that's where they were used to being fed.

Carsten went into the water among the dolphins along with Charlotte and an instructor. The instructor wanted him to wear a diving mask, but Carsten refused. After all, he wouldn't be able to see anything like Charlotte and the other visitors – he just wanted to touch the dolphins.

Before they entered the water, a man standing along the beach noticed that Carsten was deafblind, and asked him politely if he could film the encounter. We agreed and later received a copy of the footage, so Carsten now has lasting proof of his meeting with the dolphins.

Cyprus

We owe Charlotte and Grethe a huge debt of gratitude for their invaluable help in connection with our travels. Charlotte arranged a trip to Cyprus for us and several other deafblind people in 1998, and also served as travel guide. This time there was a brand new experience in store for us: deep sea diving. Before tackling the

Mediterranean Sea, however, we were first required to undergo training in the hotel swimming pool, as the instructors weren't sure whether we'd be able to handle a diving cylinder.

Carsten and his good friend Torben Hansen made their own fun by donning their diving gear and carrying on a long conversation at the bottom of the pool, but in the end, the instructor felt it was too risky for them to dive in the sea. Water had been my natural element for many years, so when the instructor saw me diving in the pool, he said that I obviously knew what I was doing. As it turned out, I was the only one of our group allowed to go deep sea diving. Charlotte, the instructor and I swam out a short distance from the beach, where we could see many beautiful rocks, reefs and plants. The instructor picked up a stone and threw it at a pile of rocks, which caused a school of tiny fish to swim out of their hiding place. It was wonderful to feel so free and be able to spend so much time in that fascinating underwater world.

When we returned to the beach, the instructor was amazed to see how much oxygen I had left in my cylinder. He said that most beginners use up their entire cylinder on a dive like ours. I was pleased to think that all my years of swimming training had prepared me for this.

One day when we went down to the beach to sunbathe and relax, I saw someone riding a water scooter. I was instantly game, but my PA was not, so I asked Morten, my former tandem bicycle partner, who had come along as a PA for another person on the tour, if he wanted to be my "pilot" again, except this time on a

water scooter. He grinned in assent, so we put on life jackets and climbed aboard. It was so much fun that I kept urging Morten to go even faster. We ended up in the water a couple of times, but I simply climbed back on and we took off again. The feel of the speed as we skimmed over the water was a life-affirming experience. However, when we got back to the beach, we were confronted with other emotions. Erna, the woman for whom Morten was a personal assistant, felt that we should have asked her permission before charging off. I confess that we hadn't given it a thought, and I did feel guilty. Live and learn!

Our trip wasn't limited to water sports, however. One day we visited a workshop for deaf people, which was near the island's Turkish border. The head of the workshop explained that he used to be the principal of a school for the deaf on the northern part of the island. However, in 1974, Turkey occupied northern Cyprus, forcing Greek Cypriots to flee to the southern part of the island. Like many other large beautiful buildings, the school for the deaf was taken over by the Turkish army, and the principal was forced to relocate.

That's when he established the workshop. He went looking for slightly-older deaf children who would benefit from the training he could offer. It wasn't a standard education, but it would give them some skills that could help them along the way. I was very touched by the man's story and impressed by everything he was doing for young people who are deaf.

Korea

One winter day in 2015, Carsten suggested that we go to a place neither of us had been to before: South Korea. I hesitated at first, reluctant to take another long flight, but I asked Carsten who I should choose as my personal assistant. He suggested Nadja, a woman who was born in South Korea and has been back many times since for language training. Although she might seem an obvious choice, I hadn't thought of her, and was actually rather hesitant about approaching her. Fortunately, she agreed to accompany us and even offered to do all the planning, as no travel agency was offering customized trips to South Korea. Carsten's regular PA Alireza had already agreed to come along. Nadja suggested we travel at the beginning of August 2016, as the weather is best then, but she met opposition from Carsten. That's when the Olympic Games in Brazil were being broadcast, and he refused to budge until they were over.

So we traveled at the end of August 2016 and stayed for about two weeks in South Korea. We had a bit of a culture shock during our first encounter with the country. We took a walk along the beach to enjoy the weather, and sensed that it was almost empty, despite the high temperature and sunshine. In Denmark people flock to the beaches whenever the weather allows. Nadja explained that being suntanned is not considered attractive in South Korea. Women always wear long sleeves, even in the hottest weather, to protect their skin from the sun. One day I was shocked by the

Carsten and Kirsten with a young Korean (hearing) teacher at the School for Deaf Children in Seoul

Kirsten and Carsten are visiting a school for deaf children in Seoul, the capital of South Korea. A young teacher is showing them around, and a farewell picture is taken of the three of them signing I Love You. Bearded Carsten is on the left wearing a baseball cap. He is signing with his right hand, while the Korean guide is signing with both hands, and Kirsten, wearing glasses, is signing with her left hand.

All three are wearing name tags suspended from a ribbon around their necks. The ribbon for the guide is a different color from those of guests. They are standing in front of a wall of photographs from various events in the school's history. One of the pictures shows the American deaf-blind author, Helen Keller, when she visited the school in the 1950s. She is standing together with school staff members.

Indoor color photograph, Seoul, South Korea, 2016. Photographer: Nadja Eun Joo Christensen.

Kirsten at the "wishing tree" in the demilitarized zone between North and South Korea. Wishes have been written on paper and suspended from bells that ring when the wind blows

Kirsten in a blue and white striped short-sleeve shirt and white slacks has a large brown leather shoulder bag and a nametag on a ribbon around her neck. She is standing next to a wishing tree in the demilitarized zone. Tourists have hung small pieces of paper with their wishes and bells, so that the arrangement resembles a Buddhist temple tree, where people similarly send their prayers to the gods to the sound of beautiful bells. Kirsten is standing with one of the wishes in her hands. She is looking seriously and thoughtfully at the photographer.

Outdoor color photograph. The border between North and South Korea, 2016. Photographer: Nadja Eun Joo Christensen, one of Kirsten's service providers, who was adopted as an infant from Korea by a Danish family.

whiteness of the face of a Korean woman who got into the elevator with Nadja and me. Nadja later explained that South Korean women not only avoid the sun, but also powder their faces white.

In Seoul, we toured the school for the deaf that Helen Keller had visited in 1937. The original building had been torn down, but a new building had been erected and a school for the blind added as well. Carsten and I were photographed along with the young deaf woman who was our guide, standing in front of a black and white photo of Helen Keller on the occasion of her visit. In the picture we're signing I-L-Y which means "I Love You" and is widely used in international sign language.

At first we thought our guide was a teacher at the school for the deaf, but she turned out to be a student doing a project on international sign language. We learned later that she was one of the school's best students, and had come there to help the hearing teachers who didn't know international sign language.

Before touring the school, we sat at an oval table in one of the rooms and talked to the guide and two hearing teachers. The guide communicated mainly with Carsten and Alireza, who knows international sign language, while Nadja interpreted for us and the two teachers. She also tried to follow their conversation in Korean as well, but they were talking very fast. Afterward, all four of us were gifted with a teaspoon and a cake fork. Having been warned in advance about the custom of gift giving, we had Little Mermaid figurines and tins of Danish cookies to give in return.

That reminds me of the time our Prime Minister paid Denmark's first official visit to South Korea in twenty-five years in 2016. I was told that he presented Korea's president with a replica of the Little Mermaid. It's obviously a favorite gift choice for Danes abroad.

The experience that made the greatest impact on me during our stay in South Korea was a visit to the demilitarized zone – a neutral area on the border between North and South Korea. We were there as part of an arranged bus tour, the only way visitors are allowed to visit the DMZ. The area, still one of the most heavily guarded in the world, is surrounded by a system of tall barbed wire fences, which the bus had to zigzag between. When we reached the DMZ itself, a South Korean soldier came on board to check our passports and make sure we were dressed appropriately in modest attire with no bare shoulders or knees, no holes in clothing and no sandals.

Visitors are also requested to behave circumspectly, with no loud talking or laughter. Photography is not allowed either, unless you've been given express permission. This is one way of showing respect for the tragedy of the Korean War, which lasted from 1950 to 1953, and in which three million Koreans lost their lives. A truce has existed since then, although the two Koreas are technically still at war.

We stayed in the DMZ for about two hours, visiting the Museum of Freedom and the Bridge of No Return, which was used for the exchange of prisoners between North and South Korea at the end of the war. The bridge got its name because prisoners of war

were given a choice: they could either remain in the country in which they were imprisoned or cross the bridge to return to their homeland. It might seem an obvious choice, yet many prisoners, with ties on both sides of the border, were torn.

In addition, more than ten million families were divided between the two Koreas. Only a few years ago was an agreement made that allowed selected family members from both Koreas to be reunited for short meetings under strict supervision. I found it very moving to stand by the bridge that symbolizes the fate of so many people. There is a beautiful park on the South Korean side that was established to honor and comfort those who have been, for whatever reason, unable to be reunited with their families .

Nadja's former language school teacher once told her a terrifying story. The teacher's friend and her husband made an attempt to flee from North Korea to China by swimming across a heavily guarded river, at the point at which the distance is the shortest.

They swam close to each other in the cold water, but were discovered by North Korean soldiers when they were halfway. Bullets fell all around them, as they swam as fast as they could. Suddenly the wife noticed a little pool of red. She thought she'd been hit, but kept on swimming. Only when she reached the bank did she realize that her husband was the one who'd been hit, and that his body was floating slowly down the river. She didn't dare stop, but continued her flight to freedom. Later she was able to flee from China to South Korea, where she still lives today.

These are heart-breaking stories, but I believe that we owe it to the people involved to hear the harsh truth.

When we returned home, I held three lectures on our experiences in South Korea at three different deaf associations. I hope others were as moved as I was to learn about the tragic events that have taken place between the two countries.

A good personal assistant is invaluable

We were extremely fortunate to be able to benefit from Nadja's experience and knowledge of the country. Without her, our trip to South Korea wouldn't have been nearly as rewarding. Oddly enough, Nadja had originally only been hired to accompany me on a one-week summer course at Castberggård back in 2013. I had asked people to put up a notice at the Center for Sign Language in Aarhus saying that I was looking for a PA for that week in the summer.

My thinking had been that surely there would be some student interpreters who would like to earn a little money during their summer vacation. Although I waited a long time, no one responded to my notice. So I asked the staff at a similar school in Copenhagen to put up a notice, and I quickly received three replies. The first was from Nadja. I arranged to meet her at a restaurant in the Copenhagen area. We quickly agreed that she would accompany me to Castberggård.

Today, in addition to her job as my permanent personal as-

sistant, she also works as an interpreter and handicap helper on Funen and in Jutland, where she now lives. You never know when you'll be fortunate enough to find a good PA. It's not just a job. There has to be a certain amount of personal chemistry and trust between the personal assistant and the employer – or user, as we are called. Otherwise it doesn't work. So Carsten and I are grateful to the good and capable personal assistants in whose company we have felt secure, even on the other side of the Earth.

19. My volunteer work for the Danish Deafblind Association

I have done various types of volunteer work for most of my life. I think it's fair to say that I really can't stop involving myself. I started at boarding school, where I was on the committee that planned parties at the dormitory, including the annual Christmas party described earlier. The work was fun and not particularly demanding. After that I was a member of the youth committee for Absalon, the youth club sponsored by the Deaf Association of 1866. We met every Friday to talk and drink coffee. I fondly remember our "coffee lady" Nina, a sweet and jolly woman who always took good care of us at meetings.

We used an old-fashioned mimeograph machine to print the club newsletter. We stapled the pages together in the middle and then folded them like a book, which seems hopelessly outdated in light of today's printing options. However, it was the best we could do at the time.

In about 1970, I helped found the Danish Deaf Youth Association on the island of Funen, for deaf people under the age of 30, and I was elected chairman in 1972. The association took part several times in the Nordic Camp for Deaf Youth, and I served as a

camp leader along with the other board members. Later the same year, I also joined the boards of the Danish Association of Deaf Artists and the Theater of the Deaf, so I was certainly juggling several balls in the air.

Looking back today, I don't understand why I got involved in so many organizations and served on so many boards at the same time. It turned out to have been a bad idea. Already in the fall of 1973, I was so burdened with my duties that I suffered from stress and ended up consulting an excellent psychiatrist, Jørgen Remvig. He advised me to resign all my posts and go live with my mother for at least a month. Stress was not really openly discussed at the time, and rumors quickly spread through the deaf community that I'd had a nervous breakdown. Fortunately, my situation was not that dire, but I doubt whether people knew the difference between stress and a nervous breakdown. Today the subject is no longer taboo, but far too many people suffer from stress.

After a short but needed break at home with my mother, I was ready to resume my volunteer work, but also a bit wiser, so I resigned from some of my duties. A year later I was employed full-time at the nursing home for deaf and deafblind people in Nærum, which automatically limited the time I was able to spend on volunteer work.

Several years later, I became a member of the Danish Deafblind Association, which was founded in 1987, and I was elected a member of the board in 1990. From the onset, I was determined

to take an active part in the association. I saw it as an important step in developing deafblind people's place in society, and as an opportunity to instigate change.

I served as vice-chairman of the association from 2003 to 2011, and then chairman until 2013. Over the years, I had many different roles, such as theater instructor, advocate for the association and member of the Social Interpreter Project. The project started in 2000 as an initiative to give deaf and deafblind people the opportunity to use interpreters in not only official but also in private contexts, and to give them the right to an interpreter in crisis situations such as hospitalization. The project was the collaborative effort of representatives from the Danish Deaf Association, Danish Association of Hard of Hearing, Danish Deafblind Association, Center on Deafness and the Ministry of Social Affairs. It ran until 2010, and resulted in the establishment of the National Interpretation Authorities, today responsible for allocating interpreters for social activities.

I still serve as an advocate, visiting nursing homes, schools and other educational institutions in Denmark, telling about the Danish Deafblind Association and life as a deafblind person. I also mention services and aids available to deafblind people and the agencies to contact for help. This is an essential service dear to my heart, and I will elaborate on it later.

In 2001, on a beautiful spring day in May, I was awarded the Ole Munk Plum Grant for my work for the Danish Deafblind Association. The grant is in memory of the man who was chairman of the

association from 1955-1978. Plum was an active, well respected chairman and also internationally engaged as vice president of the World Federation of the Deaf. He received an honorary doctorate from Gallaudet College in 1975. It was an honor for me to carry on the work of the association as he would have wished. When I arrived back in Aarhus later that day, I was met by friends who presented me with a beautiful bouquet. I was truly overwhelmed by their warm and unexpected gesture.

My work for the Danish Deafblind Association has brought me far afield and provided many experiences. In 2008 as vice chairman, I took part in the annual general meeting of the European Deafblind Union's Conference, which was held in Zagreb, Croatia, with participants from all over Europe. My PA Tina accompanied me as interpreter.

I met many interesting people during my stay, but my clearest memory is of two animals on an old farm. One of our scheduled outings took us to the farm, where we were supposed to have dinner, followed by a dance. We were given a tour of the farm when we arrived. In the stable, I discovered to my surprise a little white goose lying in the straw next to a donkey. Our host explained that the two animals had become fast friends and always sought each other's company. Finding it strange, the farmhands tried to separate the two animals, but both the donkey and the goose called out piteously to one another. Since they obviously missed each other, they were reunited and allowed to stay in the donkey's stall, with the goose guarding his friend. I found this story so touching that I took a picture of the two best friends and used it as my Christmas card that year!

At the after-dinner dance, Lex Grandia, the chairman of the World Federation of the Deafblind, played the piano and sang, despite being blind as well as hard of hearing. Lex was born and raised in Holland, but was married to a Dane and lived in Denmark. I didn't want to dance since I can't hear the music, but my two interpreters, thinking I would enjoy the entertainment anyway, had dragged me there. One of them sat in front of me and described the song in sign language, while the other "played piano" on my back, so I could sense the rhythm. I ended up having a wonderful evening, thanks to the initiative and hearty efforts of my two interpreters.

When we arrived back at the airport in Copenhagen, the two interpreters surprised me with a little souvenir: a carved wooden donkey wearing a sign around its neck that said "Pozdrav iz Hrvatske – Greetings from Croatia." I was so touched I gave their gift a place of honor on my nightstand, where it has remained to this day, to remind me of how much fun we had.

Four years later, in April 2012, we received the sad news of Lex Grandia's death at the age of sixty-one. During his lifetime, Lex had played an important role in the deafblind world. Starting in the late 1970s, he held numerous posts involving the international handicap community, and in 2006, he helped formulate the United Nation's Convention on the Rights of Persons with Disabilities, which has several direct references to deafblind people. Lex in-

spired many people, was well liked for his cheerful disposition and was greatly respected for his work for the rights of handicapped people. I attended his funeral in Aalborg as a representative of the Danish Deafblind Association.

I enjoyed my volunteer work for the association and almost always considered my work interesting and important, but it was also demanding. In spring 2013 it was my responsibility as chairman to organize and supervise twelve different arrangements and meetings in one month, a personal record, but not necessarily an enviable one.

It was a cold winter day in January 2013 that made me seriously reconsider my involvement with the association. I had gotten up early because I had a committee meeting in the Copenhagen suburbs and had to shovel snow off the stairs before I could leave. It was bitterly cold and still dark, and I was tired. After clearing away the snow, I stood waiting for the taxi that would take me to the train station for a four-hour train ride from Aarhus to Copenhagen. Naturally, taxis were also struggling with the heavy snowfall, but I managed to make it to the meeting on time, although by then I was exhausted.

For the next couple of weeks, my head was buzzing so much from all my activities that I had trouble sleeping. I wondered whether I had the necessary energy to continue as chairman. Remembering that difficult winter morning, I asked myself how many more of those I could manage. I had reached retirement

age the year before, and knew that at some future point my health would begin to decline. I needed to take better care of myself. After mulling it over for two weeks, I let the board know that I'd decided to resign as chairman due to my age and health. My resignation was officially announced at the Danish Deafblind Association's annual meeting in June 2013. I was willing, however, to continue my work as an advocate.

It was the right decision. Aside from my health, it was time to gear down and enjoy my retirement years. I also wanted to spend more time with Carsten and was actually surprised at how happy he was with my decision. I know that my involvement with the association had taken up a lot of my time, but during my twenty-three years on the board, he had never complained.

In 2012, while I was still chairman, I helped celebrate the association's Silver Anniversary, which coincided with the European Deafblind Culture and Holiday Week held at Castberggård, a perfect combination. It was a very special milestone for the Danish Deafblind Association, and as chairman, I took great pride in its development. When you consider its fragile and uncertain start, I find it impressive that it now has nearly 500 members – clear proof that there is a real need for the fellowship and support offered by the association.

The Culture Week at Castberggård was attended by almost 100 deafblind people, personal assistants and interpreters from Germany, Belgium, Hungary and the other Nordic countries. I had

met many of them the year before in Finland, when I'd been confined to a wheelchair with a broken leg, so I was delighted to be able to welcome them this time standing on my own two feet.

The Danish Deafblind Association had prepared an instruction book on haptic signing in both Danish and English, which was presented to all the participants. Many of the foreign visitors were not familiar with haptic signals, and learned to use them after their week at Castberggård, which made us very happy. This is an example of the kind of small steps we are always trying to take.

Although the primary aim of the association is to serve the deafblind community, we also want to reach out to society as a whole. To that end, in 2003 we arranged a public festival and promotion for the needs of deafblind people in a large park in Odense.

We were extremely fortunate in having the popular Danish actor and comedian Jesper Klein on the program. After his opening speech, Klein was led around, wearing a blindfold and ear protectors, to give him an idea of what it means to be deafblind. The local paper printed an article about the event, which included a picture of me guiding the helpless Klein around the park.

To attract a greater number of visitors, we also had a show going on at an outdoor market in Odense's train station. Lex Grandia played the piano, and Carsten put on a magic show with the help of two personal assistants. A deafblind consultant, Flemming Halskov, who had taught Carsten his magic tricks, stood backstage and anxiously followed his progress. The magic show attracted so much attention that it was printed up in the newspaper,

along with a great picture of Carsten as he performed in his very convincing magician's outfit.

One very good reason for trying to draw attention to the association is that not enough people are aware of its existence. Far too many deafblind people still feel alone and isolated, because they don't know that the Danish Deafblind Association can offer help, support and fellowship. The problem in particular is older people who have lost their sight and hearing later in life due to aging.

These elderly deafblind people are in fact the largest group of deafblind people in Denmark – of our almost 500 members, seven have already celebrated their 100th birthday. Studies suggest that there could be as many as 10,000 – 15,000 elderly, deafblind people in the Danish population of 5.77 million. This group finds it particularly difficult to seek and find help once their problems start growing. They have lived their lives with normal sight and hearing and are not prepared for an existence as a deafblind person. Their families are also unaware of the opportunities that exist for people who have gradually lost these two vital senses in old age. Moreover, this loss of senses in the elderly is often not considered a genuine handicap, but rather a natural consequence of the aging process. As a result, they are not offered the help they need, and their difficulties are severely underestimated. People who have lost their sight or hearing late in life need the same help as anyone else who is deafblind, regardless of their age or the reason they lost these senses. We as an association want to be as visible as possible so that we can help people out of isolation. Connecting

with people and informing them of their opportunities is precisely the job of an advocate, which is why I continue to serve in this capacity. In my opinion it's vital for every person who is deafblind to have the opportunity to live a worthwhile life, even towards the end.

So the various events held by the Danish Deafblind Association are intended to reach as many deafblind people as possible, in order to establish a fellowship and grow in strength together. Municipal reforms coupled with an increase in the aging population emphasize the need for targeted initiatives from the association on behalf of deafblind people.

20. The need for understanding

Although an appeal for understanding may sound simple, it may be difficult to achieve a true understand of what it means to be deafblind, even with the best of intentions. Most people take seeing and hearing for granted, and it is almost impossible for them to imagine a life without the two royal senses.

Unless you catch us using sign language or notice a white cane, you can't tell by looking at us that we have a handicap. We look like everyone else and are a group with "invisible" handicaps.

How people on the street perceive us is one thing. Not realizing we're handicapped, taking no notice of us could lead to misunderstandings or even accidents, but those are simply honest mistakes. A more serious situation arises when people do identify us as being handicapped, but either can't imagine the extent of the challenges we face, or worse, lose all confidence in our abilities. This is a case of ignorance or prejudice, which we may find frustrating, but have to learn to live with.

Where ignorance and lack of understand really become a problem is when they crop up in the people and agencies that control our lives: municipalities, authorities, doctors. Although their understanding is crucial, we often encounter the opposite.

In a time in Denmark when responsibility for the specialized

social sector is being transferred from regions to municipalities, seemingly to improve the lives of those with handicaps, many deafblind people have been caught in the middle. They are impacted by budget cuts, and their needs are overlooked. The sight and hearing of elderly people who have become deafblind with age are not subject to routine eligibility check-ups, which might provide them with relevant aids and personal-assistant hours. The result is isolation and loneliness.

Owing to municipal reform the Center for Documentation on Acquired Deafblindness was closed down in 2007. Having been established at the Center on Deafness in the early 1990s to gather information and promote knowledge about acquired deafblindness, the Center conducted several studies into the conditions and experiences of deafblind people. The Center collaborated effectively with the Danish Deafblind Association and the municipalities, and shared its knowledge with the relevant public sectors and service providers to ensure quality service and opportunities for deafblind people. Clearly, with the closing down of the documentation center, the deafblind community has lost a valuable ally. The Danish Deafblind Association needs to work closely with the municipalities, because there are limits to our ability to locate and help the people with acquired deafblindness who are currently under the radar.

Closure of the documentation center has also put more pressure on the Danish Deafblind Association, because we now bear sole responsibility for providing information to deafblind people

and the municipalities. Our need for volunteer advocates is greater than ever.

I remember visiting a nursing home in the Aarhus area as an advocate, where I learned to my surprise that the staff knew nothing about telecoils or other aids to help their residents with impaired sight and hearing. As a result, the staff had to spend more time with individual residents, who would have been more independent if they'd had the right aids. Nor had the residents been seen by otologists or ophthalmologists, who could have evaluated their needs. The general attitude seemed to be that old people are expected to live with their impairments and that improving their quality of life is not a priority.

Equally overlooked are the elderly deafblind people who live in their own homes. For example, they are not offered the help of a personal assistant, and even those who take the initiative and apply on their own are often turned down, although this often depends on the individual municipality. I know deafblind people who have moved to a different municipality in order to get necessary services. I find it shocking that the quality of life of deafblind people should depend so much on geography. Once again we pay the price of having an "invisible" handicap. People without specialized knowledge can find it difficult to assess the extent of our handicap, and we risk not being taken seriously.

Most people fail to understand that the loss of one or more senses leads to more than practical problems. People who lose their sight or hearing or both undergo a personal crisis highly

reminiscent of mourning. In addition to feeling cut off from the world and other people, deafblind people must often tackle such challenges as losing their jobs, their independence and thus part of their identity. I cannot emphasize strongly enough how important it is for these people to be given support and understanding. At the very least, it would be appropriate for them to be offered professional help to deal with life as an elderly person who can't see or hear.

Naturally, I want every deafblind person to be treated reasonably and considerately, regardless of whether they are young or old, or have congenital or acquired deafblindness. Yet, as I mentioned earlier, the elderly make up by far the largest group of Denmark's deafblind community. In 2015 the Danish Deafblind Association had 455 members, 342 of which were over the age of 60. It is estimated that 30% of the Danish population above the age of 80 suffers a loss of sight and hearing to some extent. The fact that the largest group of deafblind people gets the least amount of attention because of their age is a problem.

It's not only out on the street and in our dealings with municipalities that we deafblind people often feel invisible. On a recent visit to my family doctor, I discovered that I was the first of his patients to be accompanied by a sign language interpreter. I had to quickly explain why it was necessary. Luckily I've had plenty of experience doing this, so we were able to proceed to more important matters. Perhaps I shouldn't have been so surprised. Now that cochlear implants have become more commonplace, particularly

for young children, future doctors will meet fewer deaf patients. However, we mustn't forget the large group of deaf and deafblind people for whom CIs are not an option, since they will continue to be part of society for many years to come. I do find it worrying that ordinary health personnel are not used to seeing people with sense loss. Teaching medical students how to interact with patients with these handicaps would be wise. That way both sides could feel more confident when they meet.

Information is a prerequisite for understanding, and there is much to be done in this area. We cannot expect understanding from people who know nothing about our condition, and, unfortunately, general knowledge about deafblindness is limited. That's why the Danish Deafblind Association works so hard to spread knowledge about our cause. This book is my attempt to provide insight into the lives, struggles and future aspirations of deafblind people. I hope that those who are fortunate enough to have the full use of their royal senses will apply them to see us, to hear us, and to understand the challenges we face.